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Department of Mental Health

Independent Evaluation of
The Traumatic Brain Injury
Services of California

Addendum to Legislative Report

January 30, 2005

Submitted to:

Department of Mental Health
1600 – 9th Street
Sacramento, California 95814
Contact #03-73274-000

Submitted by:

Berkeley Policy Associates
440 Grand Avenue, Suite 500
Oakland, California 94610
#776



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Independent Evaluation of the Traumatic Brain Injury Services of California Executive Summary

Over 100,000 Californians visit emergency rooms each year due to head injuries, and an estimated 25% of them never return to work. To address the needs of this population, the Traumatic Brain Injury (TBI) Services of California Project is designed to “demonstrate the effectiveness of a coordinated service approach which furthers the goal of assisting individuals with TBI to attain productive, independent lives which may include paid employment.”¹ Four of the seven sites (Betty Clooney Foundation in Long Beach; Central Coast Center for Independent Living in Capitola; Mercy Healthcare, Sacramento located in Roseville; and St. Jude Medical Center in Fullerton) have been part of the TBI Project since its inception in 1990. The Janet Pomeroy Center in San Francisco was funded in 2001, while Central Coast Neurobehavior Center in Morro Bay and Making Headway in Eureka were funded in 2003. Project sites provide four core services: community reintegration, supported living, vocational supports, and service coordination.

As required by the Welfare and Institutions Code Section 4356(c), the Department of Mental Health used a competitive bid process to select Berkeley Policy Associates to conduct an *Independent Evaluation of the Traumatic Brain Injury Services of California Project*. The objectives of the evaluation were to: 1) assist in establishing a uniform participant data collection system to evaluate the effectiveness of the individual sites and the program as a whole; 2) describe each site’s service model, context, and implementation; 3) identify factors associated with program and participant success; and 4) prepare a report to the Legislature that summarizes study findings and provides recommendations for program improvement and future evaluation efforts. To achieve these objectives, the evaluation team gathered both qualitative site visit data and quantitative data on participant characteristics, service use, outcomes, and customer satisfaction.

Project Outcomes

The seven TBI Project sites served 610 participants with moderate to severe impairments from TBI in Fiscal Year 2003-2004 (FY03-04). The evaluation examined assessment data on the subset of 213 participants who enrolled in the project between February 2003 and June 2004. Evaluation results show that virtually all participants experienced at least some improvement in community reintegration after enrolling in the project, with participants at some sites experiencing substantial changes in their ability to take care of themselves at home, socialize with friends and family, and participate in community activities. Almost three-quarters of participants in the evaluation sample saw at least one improvement in their lives, whether it was securing a more stable source of income, finding a job, or moving into a more independent living situation, while only 20% experienced at least one negative change over time. The overwhelmingly positive ratings and comments that participants submitted on the evaluation’s customer satisfaction survey provide further evidence of the impact of the project on the lives of TBI survivors.

¹ California Welfare and Institutions Code Section 4353-4359: Traumatic Brain Injury Program

In addition, the TBI Project sites provided information and referral services to 7,000 TBI survivors, caregivers/family, and professionals across the state and nation. They also provided TBI education to more than 2,300 professionals and a similar number of TBI survivors and their family members in their local communities.

Recommendations for Program Improvements

The TBI Project offers great promise for addressing the critical unmet needs of TBI survivors by helping them to maintain and increase their community reintegration, while also providing significant community education services. **The evaluation's overarching recommendation is to expand the funding for the TBI Project to enable it to reach many more persons with TBI throughout the state.** The additional recommendations presented below recognize the value of the TBI Project's contribution, while also acknowledging that the program can be improved in a number of areas and that the evaluation was limited in its ability to document outcomes by the available data and resources. Study results suggest the program is sufficiently successful that its expansion to reach more participants would be a good investment, but only if part of that investment is also targeted at program improvements to increase program benefits, and to improve data collection and reporting efforts to document those benefits.

Recommendation #1: Build specific service design considerations into state-level cooperative agreements, such as specifying that the Department of Rehabilitation use specialist counselors as liaisons to the project sites. Be sure that memoranda of understanding (MOUs) and cooperative agreements address state/local communication and hold local staff accountable for implementing the agreements.

Recommendation #2: Shift toward more of a "systems approach" to service delivery that identifies the spectrum of services that should be in place to meet the needs of persons with TBI, and uses a systematic community needs assessment process to identify resources and gaps.

Recommendation #3: Use ongoing program evaluation to: 1) identify promising and transferable practices; 2) provide technical assistance; 3) support mentorship and sharing of information and resources among sites to maximize effective use of lessons learned; and 4) continue to document outcomes that take a year or more to accomplish. Improve the project's data systems to better link services and outcomes to the larger project goals, objectives, and performance measures.

Recommendation #4: Include independent living skills training that emphasizes improving compensatory skills within the core services provided by the project. Identify a common prevocational/vocational assessment tool to identify work readiness skills and needs, and train staff in how to administer it. Train site staff on using specific tools to identify participants who have potential substance abuse problems.

Recommendation #5: Improve routine monitoring reports that provide information across the project as a whole as well as for each site, and provide timely feedback on performance to the sites. Use performance information to identify areas of technical assistance needed by the sites and to inform funding decisions. Re-compete the contracts periodically to encourage continuous program improvement.

Recommendation #6: Increase funding for sites in areas with large underserved communities. Require sites to specify in their funding proposals how they will ensure the population they serve is increasingly representative of the racial and ethnic diversity of their local communities. Train site staff in strategies and resources for accommodating participants with limited English proficiency.

1. Introduction

Each year, an estimated 108,698 Californians visit the emergency room because of a traumatic brain injury (TBI)¹ caused by an external force to the head. Over 20,000 California residents are hospitalized annually because of such injuries, and at least 7,000 become permanently disabled as a result of a TBI. According to the Centers for Disease Control, approximately 25% of adults who experience TBI are unable to return to work one year after injury.²

In recognition of the lasting impacts of TBI on California residents and their families, the State Legislature provided funding in 1988 for a pilot project offering a continuum of services for TBI survivors and their families. The project is administratively located within the state Department of Mental Health, which is required by the legislation to contract with community-based

Traumatic Brain Injury Services of California Collective Goals

1. Achieve comprehensive, coordinated public policy to design a coordinated services delivery system for adults with traumatic brain injuries;
2. Ensure the existence of an array of appropriate programs and services for adults with traumatic brain injuries and their families;
3. Place a high priority on utilizing community resources in creating opportunities for persons with TBI to live in the community and achieve their maximum potential, and for families to maintain a brain injured adult at home when possible or in other community-based alternatives when necessary;
4. Assist persons with TBI to attain productive, independent lives, which may include paid employment;
5. Participate in a statewide uniform database for the TBI program in order to measure the effectiveness of the TBI sites and a coordinated service approach, as well as monitor the progress of the statewide implementation of Chapter 1023, Statutes of 1999 (AB 1492); and
6. Serve a population that is broadly representative with regard to race and ethnicity of the population with traumatic brain injury in the geographical service area.

(Source: TBI Site Contracts Scope of Work)

organizations to operate service sites. The project originally included four sites designed to “demonstrate the effectiveness of a coordinated service approach which furthers the goal of assisting individuals with TBI to attain productive, independent lives which may include paid employment.”³

Subsequent legislation expanded the TBI Project to include a total of eight sites, contingent upon the availability of funds. The new law increased the project’s overall funding, and extended authorization for funding through June 2007. In addition, the legislation called for an independent evaluation of the efficacy of project services.

In August 2003, California’s Department of Mental Health (DMH) awarded Berkeley Policy Associates (BPA) a contract to conduct the *Independent Evaluation of the Traumatic Brain Injury (TBI) Services of California Project* using a competitive bid process, as

¹ Estimates from CDC TBI Surveillance Grant Program and NCHS data, compiled by the Brain Injury Association of America. Cited in *California Traumatic Brain Injury State Grant Program Fact Sheet*, September 2002.

² Centers for Disease Control and Prevention, *The Injury Fact Book, 2001 – 2002*.

³ California Welfare and Institutions Code Section 4353-4359: Traumatic Brain Injury Program

required by the Welfare and Institutions Code Section 4356(c). This report presents the findings of that evaluation. The remainder of Chapter 1 discusses in more detail current project sites, the core services provided by the sites, and funding sources used to support the project. Next, we present an overview of the evaluation's design and methods, and finally outline the contents of the rest of the report.

TBI Project Sites

The TBI Project currently has seven sites across the state (see Figure 1.1), including those operated by: the Betty Clooney Foundation in Long Beach; the Central Coast Center for Independent Living in Capitola; Central Coast Neurobehavior Center in Morro Bay; Making Headway in Eureka; Mercy Healthcare, Sacramento located in Roseville; St. Jude Medical Center in Fullerton; and Janet Pomeroy Center, (formerly RCH, Inc.) in San Francisco.

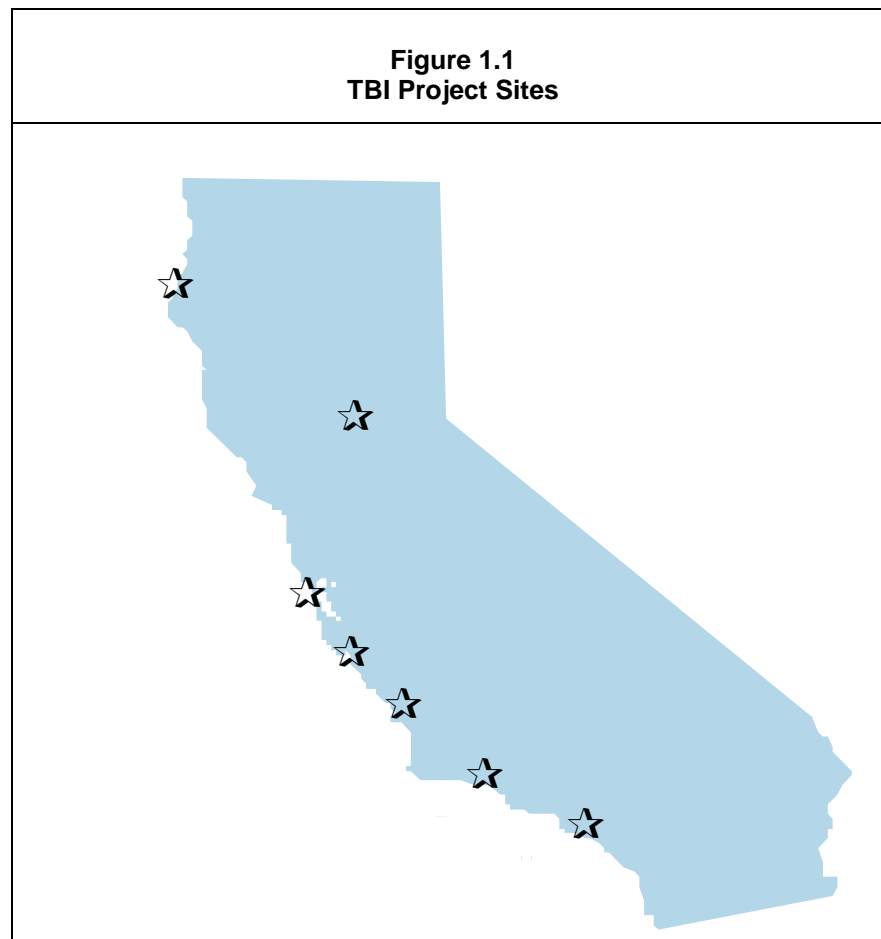


Figure 1.2 lists the project sites, their location and service areas, and the year they were awarded contracts. The figure also shows the abbreviated name used for each site for the remainder of this report.

Four current sites (Clooney, CCCIL, Mercy, and St. Jude) have been with the TBI Project since its inception in 1990. DMH awarded Pomeroy's contract in 2001, while Headway and CCNBC sites have been in operation for less than two years.

Two of the sites—Mercy Healthcare, Sacramento and St. Jude Medical Center—are hospital-based, while other types of community-based organizations operate the rest. As Chapter 2 will discuss, the sites have adopted diverse approaches to service delivery and coordination.

Figure 1.2 TBI Project Sites				
Grantee	Project Name	Location, Service Area	Year of Contract Award	Referred to in this report as:
Betty Clooney Foundation for Persons with Brain Injury	<i>Project Connections</i>	Long Beach, Los Angeles County	1990	Clooney
Central Coast Center for Independent Living	<i>New Options</i>	Capitola, Santa Cruz County	1990	CCCIL
Central Coast Neurobehavior Center	<i>OPTIONS</i>	Morro Bay, San Luis Obispo & Santa Barbara Counties	2003	CCNBC
Making Headway, Inc.	<i>Making Headway</i>	Eureka, Humboldt, Del Norte, & Mendocino Counties	2003	Headway
Mercy Healthcare, Sacramento	<i>Coordinated Care Project</i>	Roseville, Sacramento, Placer, & Yolo Counties	1990	Mercy
St. Jude Medical Center	<i>St. Jude Brain Injury Network</i>	Fullerton, Orange County	1990	St. Jude
Janet Pomeroy Center (formerly RCH, Inc.)	<i>San Francisco TBI Network</i>	San Francisco, San Francisco County	2001	Pomeroy

Mandated Project Services

The target population for project services is adults who have sustained an external blunt force to the head that has resulted in cognitive, psychological, neurological, or anatomical changes in brain function. To be eligible for TBI Project services, TBI survivors must be over age 18 and reside within the service area of one of the seven sites.

As the funding legislation points out,⁴ lack of awareness of the wide range of problems associated with head injury have resulted in a significant lack of services for persons with head

⁴ *ibid*

injuries and, in particular, a serious gap in post-acute services. Although a number of different programs currently attempt to meet various types of needs experienced by persons with head injuries, no single state agency is clearly assigned ultimate responsibility for ensuring that the needs of individuals with TBI are met comprehensively.

The sites are charged with implementing the following objectives:⁵

- Provide to adults with traumatic brain injury: supported living services, community reintegration services, service coordination, and vocational support services.
- Provide to families, caregivers, and professionals: information, advice and referral services, and family and community education.
- Provide outreach activities to meet the cultural and ethnic needs of the population with traumatic brain injury in the geographic area served.
- Work closely and coordinate with organizations serving persons with traumatic brain injury, their caregivers, and families, in order to ensure that the greatest number of persons are served and that the greatest number of organizations participate.
- Assist in the identification and documentation of service needs and the development of necessary programs and services to meet the needs of adults with traumatic brain injuries in the geographic area served.
- Cooperate with DMH in any activities deemed necessary for the proper implementation of Section 4356 et. seq. of the Welfare and Institutions Code, and comply with all reporting requirements through reports on demographic, assessment, service utilization, resources, and outcome data collected in the provision of TBI services.

The TBI Project is designed to provide programmatic coordination among agencies to facilitate the provision of a continuing range of services appropriate for persons with traumatic brain injuries. Thus, the sites use a coordinated service model, drawing upon existing community-based services to supplement the services that site staff provide directly. This approach offers an efficient means of addressing the complex functional impairments that many TBI survivors face.

Core services mentioned both in the legislation and in the TBI Project objectives listed above include:⁶

- **Community Reintegration Services.** Assistance designed to develop, maintain, increase, or maximize independent functioning, with the goal of the recipient living in the community and participating in community life. These services may include, but are not limited to, providing or arranging for access to housing, transportation, medical care, rehabilitative therapies, day programs, chemical dependency recovery programs, personal assistance, and education.

⁵ TBI Site Contracts Scope of Work.

⁶ Definitions and Reporting Procedures, Traumatic Brain Injury Project Site Statistics Fiscal Year 2002-03. These also can be found at <http://www.dmh.cahwnet.gov/SpecialPrograms/TBI/background.asp>.

- **Family and Community Education.** Provision of information designed to improve overall understanding of the nature and consequences of TBI, including public and professional education designed to facilitate early identification of persons with TBI, prompt referral of these persons to appropriate services, and improvement of the system of services available to them.
- **Services Coordination.** Assessment and identification of participant's special needs and problems, including the development and planning of services to meet such needs. Services coordination should: 1) be participant driven; 2) extend participant empowerment; 3) provide ongoing support and encouragement; 4) afford personal advocacy and outreach when necessary; 5) maintain linkages to services; 6) monitor progress; and 7) provide for reassessment.
- **Supported Living Services.** A range of appropriate supervision, support, and training in the participant's place of residence, designed to maximize independence. Residence is defined as the place where a participant makes his or her home, including a house or apartment where the participant lives independently, assisted living arrangements, congregate housing, group homes, residential care facilities, transitional living programs, and nursing facilities.
- **Vocational Supportive Services.** Methods for providing vocational rehabilitative and related services that may include prevocational and educational services to individuals who are not served or are underserved by existing vocational rehabilitation services. Vocational supportive services differ from traditional vocational rehabilitation and day activity services in the following four areas: 1) service participants appear to lack the potential for unassisted competitive employment; 2) ongoing training, supervision, and support services are provided; 3) the opportunity is designed to provide the same benefits that other persons receive from work, including an adequate income level, quality of working life, security, and mobility; and 4) provision of support is flexible, which is necessary to enable the participant to function effectively at the work site.

TBI Project Funding

The TBI Project is supported by funding from several sources including the California Traumatic Brain Injury Fund, a 20% match from the organizations operating each site, and for some sites, a cooperative agreement with the state Department of Rehabilitation (DR). We briefly describe each of these below.

California Traumatic Brain Injury Fund. The major source of funding for the TBI Project is the state's Traumatic Brain Injury Fund, established by Section 1464 of the Penal Code. This legislation stipulates that 0.66% of the state penalty funds imposed upon every fine, penalty, or forfeiture collected by the courts throughout the state for criminal and vehicular offenses be contributed to the TBI Fund. In addition, fines collected for violation of California's seat belt law support the TBI Project. Initially, Section 1464 of the Penal Code capped the amount to be contributed to the TBI fund to \$500,000. The four sites in operation at that time shared this amount. In 2000, however, subsequent legislation lifted the cap so that the TBI Fund would

receive the full 0.66%. This change was retroactive to Fiscal Year 1997-98. Each of the seven current sites receives \$150,000 per year from the TBI Fund.⁷

Contractor Matching Funds. The 20% match from each site's host organization contributes another \$30,000 per year to the operation of each site. All of the sites make the match through in-kind contributions of staff time and/or other direct costs. For three sites (CCCIL, CCNBC, and Mercy), contributions consist solely of administrative and service staff time, while the other sites also contribute office space and equipment (computer and telephone), utilities, supplies, travel costs, and postage toward the 20% match.

Vocational Rehabilitation Funds. DMH also supports the TBI Project in providing vocational services through an interagency cooperative agreement with the California Department of Rehabilitation (DR). This agreement allows DMH to use TBI Fund resources and in-kind services from the sites as a match for federal Vocational Rehabilitation funds. Thus, sites that choose to participate in this agreement provide \$30,000 in match funds to secure an additional \$120,000 in federal funding to cover vocational assessment and personal, vocational, and social adjustment services for project participants who are eligible for DR services. In addition to funds channeled into site budgets, the interagency agreement also secures extra federal funds for DR counselor time and case services for the TBI site's participants.

Four of the sites—CCCIL, Clooney, Mercy, and Pomeroy—have participated in the cooperative agreement since it was first introduced. In addition, at the time of the evaluation site visit, CCNBC was negotiating to be added to the agreement. During the evaluation period, however, only Mercy and Pomeroy were actively participating in the interagency agreement (see Chapter 2).

The interagency cooperative agreement uses two different contracting mechanisms to cover the provision of vocational services through the TBI Project, depending upon whether or not the site's host organization is a DR vendor. Mercy (and formerly Clooney and CCCIL) has a subcontract with DMH to provide services through the cooperative agreement. On the other hand, the agreement channels funds to Pomeroy, a DR vendor, through the organization's case service contract with DR.

Evaluation Design and Methods

Section 4356(c) of the Welfare and Institutions Code requires DMH to conduct an independent evaluation of the TBI Project and to assist sites in collecting uniform data on all participants. The legislation requires the evaluation to test the efficacy, individually and in the aggregate, of the existing and new project sites in the following areas:

- The degree of community reintegration achieved by participants, including their increased ability to independently carry out activities of daily living, increased participation in community life, and improved living arrangements;

⁷ Clooney receives an additional \$50,000 annually to operate the statewide TBI Hotline (see Chapter 2).

- The improvement in participants' prevocational and vocational abilities, educational attainment, and paid and volunteer job placements;
- Participant and family satisfaction with services provided; and
- Number of participants, family members, health and social service professionals, law enforcement professionals, and other persons receiving education and training designed to improve their understanding of the nature and consequences of traumatic brain injury, as well as any documented outcomes of that training and education.⁸

The objectives of the evaluation build directly upon these requirements. They are to:

1. Assist the programs in establishing a uniform participant data collection system that can be used to evaluate the effectiveness of the individual sites and the program as a whole;
2. Describe each program's service model, context, and implementation;
3. Identify factors associated with program and participant success; and
4. Prepare a report to the Legislature that summarizes study findings and provides recommendations for program improvement and future evaluation efforts.

To achieve these objectives, the evaluation team conducted several different types of data collection, gathering both qualitative site visit data and quantitative data on participant characteristics and outcomes. BPA staff conducted visits to each of the seven sites to interview project staff about the implementation of the projects and the design of specific post-acute continuum of care models. We also interviewed participants and their families about the services they used and their satisfaction with those services. Finally, we talked with staff from local agencies with whom the sites collaborate, regarding their working relationships with the sites; specific collaboration efforts and roles; the project's impact on participants, caregivers, and the community; the site's innovative or promising practices; lessons learned about working with individuals with TBI or implementing collaborative efforts; and any suggestions for improvement.

The evaluation used three sources of quantitative data. First, the sites provided the study team with individual-level data on characteristics, service needs, and outcomes for a subset of their participants. Second, we analyzed TBI Project quarterly site statistics on numbers of participants served and services provided. Third, with the assistance of site staff, we conducted a survey of participants assessing their satisfaction with project services.

We discuss data collection methods further in subsequent chapters of this report. In addition, Appendices A, B, and C include the data collection instruments and protocols used in this study.

⁸ Section 4356(c) also required the evaluation to assess "The extent to which participating programs result in reduced state costs for institutionalization or higher levels of care, if such an estimate can be obtained within the 10 percent of funds allowed for the evaluation." The cost study could not be conducted within this budget, and DMH excluded it from the study's scope of work.

Overview of the Report

The rest of this report is organized into six chapters, followed by three appendices consisting of the evaluation's data collection instruments and protocols, as follows:

- Chapter 2 describes the seven TBI Project sites, their local communities, range of services provided, staffing, and participants.
- Chapter 3 presents a snapshot of participants served by the TBI Project as a whole, focusing on those who enrolled during the 2003-2004 fiscal year.
- Chapter 4 discusses the impact of site services in terms of the outcomes achieved by the subset of participants who enrolled during Fiscal Year 2003-2004.
- Chapter 5 describes the results of the evaluation's customer satisfaction survey, supplemented by input from participants and family members during site visit interviews.
- Chapter 6 gives an overview of the impact of the TBI Project sites on the programs' local communities.
- Chapter 7 summarizes the evaluation's key findings and presents recommendations for program improvements and future evaluation efforts.
- Appendix A-1 presents supplemental tables on the evaluation's study sample, by site.
- Appendix A-2 includes supplemental tables on Fiscal Year 2003-2004 site statistics, by site.
- Appendix A-3 is a supplementary table on findings from the evaluation's participant satisfaction survey, by site.
- Appendix B contains the TBI Project's assessment and intake forms.
- Appendix C consists of the customer satisfaction survey instrument and protocols.
- Appendix D includes the study's site visit protocol and interview topic guides.

2. Description of the TBI Project Sites

Introduction

While the seven TBI Project sites all provide the same core services using a collaborative service coordination model, they vary significantly in their approaches to providing these services. A range of service organizations operate the sites, and each brings a slightly different emphasis to their work with TBI survivors.

This chapter first gives an overview of the group of TBI Project sites, examining similarities and differences in their structures and service mix, and strengths and challenges common across the sites. The second section of the chapter consists of a brief profile of each site.

Overview of the TBI Project Sites

All of the agencies that host TBI Project sites are nonprofit organizations that vary widely in terms of budget and size. The two largest host agencies are Mercy and St. Jude; each of these hospitals has a multi-million dollar budget and hundreds of employees. In contrast, Clooney and Headway each have a handful of employees and total annual budgets well under \$500,000. In these last two sites, the TBI Project contract represents at least half of the host organization's annual budget. Both Clooney and Headway target their services specifically to TBI survivors. Their size and funding levels may be a reflection of the level of attention and funding dedicated to individuals with TBI in general.

The three remaining sites (CCCIL, CCNBC, and Pomeroy) are all operated by organizations that focus on serving more general populations of people with disabilities, and have annual revenues of between one and ten million dollars. As an independent living center, CCCIL serves individuals with a range of disabilities, while CCNBC and Pomeroy have historically targeted their services to people with developmental disabilities.

The host agencies of two sites have CARF (Commission on Accreditation of Rehabilitation Facilities) certification. Both the CCNBC and Pomeroy organizations also are Department of Rehabilitation vendors.

The sites also vary in the number of participants they serve per year, and these numbers are somewhat reflective of the population of each site's service area. Participants served by Clooney, located in Los Angeles County, represented more than half of all those enrolled in the TBI Project in FY03-04. Making Headway is located in Eureka and started serving participants halfway through the fiscal year. With only six months of service provision, and given its rural, relatively isolated location, it is not surprising that Headway participants represented approximately 5% of those served by the TBI Project.

As would be expected given the emphasis of the funding legislation, the sites' service models are predominantly based on provision of case management/service coordination services. Several sites, however, integrate provision of additional services in their service models, along with core services. For example, Mercy includes the provision of rehabilitation therapies in its service package, while Headway includes psychological counseling. When sites offer assistance beyond the core services specified in the funding legislation, the additional services usually are those that the host organizations provided before they signed their TBI Project contracts.

All of the sites offer services designed to meet the individual needs of participants, but a few of the sites organize at least part of their services into a recognizable "program" with a distinct progression of different service "steps." These sites are included under the interagency cooperative agreement between the Department of Mental Health (DMH) and the Department of Rehabilitation (DR). Mercy and Pomeroy currently are covered by the agreement, and CCNBC has applied to be included.

While the funding legislation directs the TBI Project to serve caregivers as well as TBI survivors, the sites tend to focus most of their resources—and staff time in particular—on serving individuals with TBI. Even so, three sites (CCNBC, Headway, St. Jude) have contracts or memoranda of understanding (MOUs) with local Caregiver Resource Centers to provide supportive services to family members and other caregivers. In addition, two other sites (CCCIL, Pomeroy) have informal agreements with the centers to assist the caregivers of TBI survivors.

Strengths and Challenges

A major strength of the TBI Project sites is the excellent qualifications of their staff. Although the types of qualifications vary across the sites, all sites have recruited or assigned staff to the project who have significant and relevant backgrounds. Some staff members bring to the project relevant professional training in clinical services, social work, or rehabilitation. Other staff are qualified on the basis of their accumulated experience in working with TBI survivors over a number of years, or their personal experiences as TBI survivors.

Interview respondents at every one of the TBI Project sites noted that providing quality services within their contract budgets is a big challenge. Personnel from at least two of the sites are proud of what they have been able to accomplish with limited resources, "doing so much with so little." The four original sites have seen their contract budgets unchanged for most of the 14 years they have been funded, and staff pointed out that with cost of living increases over time, in effect their funding levels have decreased.

The ability to do so much with so little is indicative of the level of commitment to assisting TBI survivors that is shared by staff at all of the TBI Project sites. Collaborators at all of the sites remarked on this quality in discussing the TBI Projects and their staff, and several called it the "passion." Nonetheless, maintaining the vision, the passion, and commitment over time can be a challenge for project staff. In particular, maintaining this vision and commitment may challenge the site as a whole when there is turnover among key staff.

Finally, as a group the sites face the challenge of determining whether they represent a cohesive program or a collection of individual projects. In interviews at almost every site, staff brought up

questions related to consistency of service procedures and the participant information they collect, as well as the degree to which they share information within the group.

TBI Project Site Profiles

Each of the site profiles below includes two parts. The first is a narrative describing the site's staffing, services, funding, collaboration and community education, and strengths and weaknesses. Second, the profile includes a tabular "profile summary" that presents information about the site's participants who were part of the evaluation's study sample. Information included in the profiles reflects staffing and other arrangements as of the time of the evaluation's site visits (see Appendix D for the site visit schedule).

Project Connections, Betty Clooney Foundation for Persons with Brain Injury

The Betty Clooney Foundation was one of the original four TBI Projects that began operating in 1990. Located in Long Beach, the program serves individuals with brain injury from throughout Los Angeles County. In addition to TBI Project services, the Foundation offers: a day activity program; art, music, and exercise classes; support groups; employment preparation; service coordination services; and animal-assisted therapy. Despite the county's size, density, and number of service providers, the Foundation is the only provider of information and referral or service coordination services for TBI survivors in Los Angeles County. The site uses a medically-oriented case management service model.

Staffing

The TBI Project has three full-time staff members, plus a percentage of a secretary's time. Clooney's executive director holds a Master's degree in Social Work from UCLA. In addition to leading the organization, she provides community education and service coordination services. The project director, who holds a Master's degree in Rehabilitation, also provides both of these services. The third staff member is a full-time service coordinator, who also handles the TBI Toll-Free Hotline, which Clooney operates with extra funding from DMH.

Participant Services

Clooney does not have a waiting list for services. Both the project director and the service coordinator complete intake forms for all information and referral calls in order to have documentation of the types of callers and needs discussed during the call. All three staff complete participant assessments based on the TBI Project's common assessment form. If the participant needs a vocational assessment, staff use an additional form to guide this part of the interview.

Clooney's Individual Service Plans (ISPs) most frequently include independent living and housing goals. The plans include a date to review the participant's progress. On the review date, the timeline for accomplishing tasks may be revised, the plan may be signed off as completed, or the participant may add additional goals to the plan.

The site refers participants to other community resources for many types of community reintegration services, but staff members provide mobility training themselves. The staff believe

that the heart of community reintegration is allowing participants to make their own choices, and allow them the dignity of making their own mistakes. Thus, they try to intervene in a situation only when a hazard is involved.

Service coordination often involves providing advocacy and/or moral support. Both of the two senior personnel accompany participants to hearings, SSI appeals, arbitration, or to court, although the project director most often takes on these tasks. On the other hand, many participants live independently and never come into the office. Staff members check in on these individuals about once per month.

Supported living services for some participants include assisting them in supervising and paying an In-Home Support Services (IHSS) provider. For these participants, site staff divide tasks such that one staff member assists with managing the service provider, while the other coaches the participant on money management. Other supported living assistance that Clooney provides includes help in moving out of a skilled nursing facility (SNF) or parent's house, or reminders about personal hygiene.

Site staff offer support groups on an as-needed basis, depending upon participants' level of interest and the times that are convenient. Staff members ask participants for a commitment before they schedule the group. Scheduling support groups also depends upon the availability of someone to facilitate the group—either interns from the UCLA Master of Social Welfare program, or Clooney's executive director. The location of these groups varies, and they often include a presentation by a guest speaker. Clooney also refers participants to support groups run by other collaborating agencies, including Gentiva, an outpatient rehabilitation facility that allows Clooney participants to attend its support groups at no charge.

Staff currently provide vocational support to participants who are interested in employment and those who are working. This support takes the form of referrals to DR and the California Employment Development Department (EDD) for employment services, as well as follow-along contacts and re-training for those participants currently employed. Several participants currently hold volunteer positions, including a few who volunteer at the Clooney office. For example, one participant takes care of copying and mailing, while another cleans up the outside of the building and tends the small garden.

Clooney operates the TBI Project's Toll-Free Hotline, which provides information and referral services to callers from throughout California and the nation. Last year, the Hotline responded to 6,457 requests for information. The majority (82%) of these were from callers in Southern California, and another 15% were from callers located outside of the state. Two-thirds of the calls were from family members and caregivers of TBI survivors.

Funding

In addition to the \$150,000 per year that Clooney receives from DMH to operate the TBI Project site, the organization also receives \$50,000 from DMH to run the TBI Toll-Free Hotline. The site's host organization contributed significantly more than 20% in in-kind contributions to the project. The site's 2003-2004 budget shows the Foundation contributing a total of \$121,696 in

matching funds. Nonetheless, funds from DMH represent almost half of the organization's total annual budget.

Collaboration and Community Education

Clooney collaborates with over 60 agencies located throughout Los Angeles County, including disability organizations, service providers, senior centers, acute and rehabilitation hospitals, independent living centers, and others. For example, the site exchanges resources and referrals with the Westside Center for Independent Living in Los Angeles. Staff also share service coordination of participants who are dually diagnosed with both TBI and mental illness with a local mental health program. The site also belongs to the Carson Coordinating Council.

Clooney withdrew from the interagency cooperative agreement between DMH and DR in September 2003. Although the site had worked collaboratively with DR under the agreement for a number of years, the situation changed when the Long Beach DR office closed and administration of the cooperative agreement at the local level transferred to a different DR office. Site staff were concerned that personnel at the new DR office seemed to lack knowledge about the cooperative agreement and understanding of the vocational challenges that TBI survivors face. As a result of dropping out of the agreement, Clooney has decreased the intensity of the employment services offered to participants.

The site has also somewhat reduced its community education activities as a result of the reduction in its funding related to withdrawal from the interagency agreement. Clooney's project director participated on a number of committees, and provided training on TBI to local police departments, parole officers, women's groups, and several Lutheran schools. More recently, the site has not provided any community education seminars or workshops; however, the project director has continued his participation in disability and community committees, though at a somewhat reduced level of involvement.

Strengths and Challenges

Clooney's TBI Project benefits from the fact that the organization's other funding is relatively unencumbered, and thus can be used flexibly to meet participant needs. Senior staff members have a long history of working with TBI survivors, and the level of acceptance that staff have for participants, their challenges, and their rate of progress is key to the project's success.

Although the project director is Hispanic and bilingual, the site serves relatively few Hispanics. Increasing the number of bilingual hospital staff, individuals able to sufficiently explain to patients why they need Clooney services, might increase the number of Hispanics referred to the site. Nonetheless, the low number of Hispanic participants also points to the need for targeted outreach to this population.

The limited funding available to the TBI Project sites may be more challenging to Clooney than to other sites. Staff noted that despite the fact that their service area is the most populous area of the state, they receive the same level of funding as the other TBI Project sites.

Figure 2.1 SITE PROFILE SUMMARY: Project Connections, Betty Clooney Foundation	
Site Characteristics: <ul style="list-style-type: none"> Host Organization Years Providing CA TBI Project Services CA TBI Project Funding as Percent of Organization's Budget Service Area 	Betty Clooney Foundation For Persons With Brain Injury 14 years 51% Los Angeles County
Participants Served: Unduplicated Count of Participants PY 2003-2004	316
Number of Participants in Study Sample ^a	53
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> Average Age Percent Male Percent Minority Percent High School or Above Percent Married Percent with SSI/DI Average Income ^b Client of Department of Rehabilitation Percent Employed Percent with Desire to Work 	43 years 60% male 30% minority 84% Diploma/GED or above 28% married 59% SSI or SSDI \$193.71 29% DR 2% 26%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> Average Age at Injury Average Time Since Injury at Intake Motor Vehicle Accident TBI Substance Abuse Related Participants with Coma Average Duration of Coma Participants with Limited Mobility Participants with Pain 	31 years 11.4 years 55% 26% 57% 59 days 53% 19%
Services Provided (% Sample Receiving Each Service) at 6 Months: <ul style="list-style-type: none"> Percent Receiving Service Coordination Special Evaluation Living Assistance Mental Health Services Substance Abuse Treatment Social/Recreational Services Supported Employment Employment Services Education Services 	100% 6% 25% 28% 17% 42% 4% 8% 0%
Participant Outcomes: <ul style="list-style-type: none"> Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> Average Percent Change in Home Score Average Percent Change in Social Score Average Percent Change in Productivity Score Increase in Day Program Participation Increase in Educational Status Maintained Employment Obtained Employment 	+62.6% +13.6% +22.6% +19.3% 43% 2% 0% 0%

^a The study sample consists of participants who enrolled between February 2003 and June 2004. Assessment information was only available for participants who had six-month follow-ups. Thus, 24 participants with only initial intakes were not included in the analysis.

^b Income data available for only 21 participants.

New Options, Central Coast Center for Independent Living

The Central Coast Center for Independent Living (CCCIL) is an independent living center serving people with disabilities in Santa Cruz County. The organization's services include: independent living information and referral; advocacy; housing assistance; personal assistance services; peer support; independent living skills and life skills training; community and systems advocacy; and assistive technology. CCCIL is located in Capitola, a small city adjacent to the City of Santa Cruz. The site serves all of Santa Cruz County, which is predominantly suburban, with outlying rural areas. Santa Cruz is home to one of the University of California campuses, and housing is expensive. Very little low-income housing is available. The organization has hosted the TBI Project since the program was first implemented in 1990. CCCIL's service model provides service coordination flavored by the independent living philosophy.

Staffing

The TBI Project budget covers two full-time (or nearly full-time) staff members: a service coordinator, and a community re-entry specialist. Both are TBI survivors, and both provide service coordination and facilitate support groups. In addition, the contract covers small proportions of staff time for the host organization's executive director, independent living services manager, accounting manager, office assistant, and an independent living specialist trainee. The independent living services manager provides oversight for the project, and both he and the service coordinator have backgrounds in education and provide community education services.

Participant Services

Both the service coordinator and the community re-entry specialist field phone calls for information and referral. Staff tend to screen TBI survivors and/or their family members on the phone before completing an intake, and often complete the intake and assessment at the same meeting. They conduct assessments based on the TBI Project's common assessment form. The site does not have a waiting list for services.

In developing the ISP, the service coordinator sees herself as a member of a team with the participant as boss. She gives the participant options, and hopes the individual makes the best choices among the options presented. An important part of the planning process is redefining goals into small steps that can be achieved in three to four months. This short-range timeframe allows participants to see their progress. As a result of this approach, staff generally update service plans every three to six months. Nonetheless, staff noted that participant progress may not always be measurable at follow-up assessments, or may not be a linear process.

Service coordination and participant advocacy comprise a major part of the job of both the service coordinator and the community re-entry specialist. Participants frequently need assistance with applying for SSI, Medicaid, food stamps, low-income housing, or other benefits. Once such needs have been addressed, CCCIL staff members generally meet with participants about once per month on an ongoing basis.

As part of the supported living services offered by the site, staff provide compensatory skills training for participants who either have undiagnosed TBIs or who experienced their injuries

many years ago. Staff also provide independent living skills training on topics such as organization and developing routines.

CCCIL's TBI Project offers three support groups per month, all led by staff with a TBI, and each with a different focus. The service coordinator facilitates the social support group, which meets at a local coffee house. Both the service coordinator and the community re-entry specialist facilitate another group held at a skilled nursing facility for its residents and for group home residents. The third TBI survivors group meets at United Way, and is facilitated by the community re-entry specialist. This group focuses on problem-solving for TBI survivors. CCCIL helped the local Parks and Recreation Department design and develop a Leisure Club for people with TBI that meets weekly.

Staff provide career exploration or resume preparation assistance at participants' request. Nonetheless, the focus of CCCIL's vocational supports is to help make the participant's living situation stable so that work is actually feasible. This may involve working with participants to develop pre-employment skills such as organization, timeliness, and developing socially acceptable behavior.

Funding

The DMH grant and its attendant matching funds from CCCIL are the site's sole source of funding. In total, the annual budget is \$180,874, including an in-kind match of \$30,000 from the host organization.

Collaboration and Community Education

CCCIL serves as convener for the "New Options Consortium," a group of approximately 15 organizations that provide services to TBI survivors. Members of the consortium include the Del Mar Caregiver Resource Center, Cabrillo College, DR, Linkages, Watsonville Community Hospital, and other service providers. The consortium meets intermittently for TBI education, case conferencing, and outreach/presentations on services offered by the site. The service coordinator described the program as being the "spider in the web" of the consortium, connecting participants to existing community services.

The site also holds quarterly "Life After Brain Injury" sessions for both survivors and families, although these meetings are open to anyone. Each session has a different guest speaker. The focus of these presentations tends to be on finding one's inner strengths.

TBI Project staff have provided community education on TBI for a local rehabilitation hospital, and homeless and mental health organizations. The independent living services manager has conducted two seminars on TBI with local police departments. In addition, other site staff trained the Capitola police department in disability awareness using a panel discussion with people with disabilities, including a TBI survivor.

Outreach for the TBI Project is folded into CCCIL's general outreach activities. Every time CCCIL personnel make a presentation on the center's services, a discussion of the TBI Project is always included. Staff conduct outreach at numerous community activities including various hospitals, medical clinics, and the "Day on the Beach with Foster Anderson" (a local nonprofit

recreation program for people with disabilities). Other outreach activities have included the service coordinator making a presentation at a local school with the police bike patrol on TBI and the importance of wearing helmets and protective equipment. In addition, the independent living services manager writes regular columns for three local newspapers about brain injury and its effects on survivors.

CCCIL participated in the interagency cooperative agreement between DMH and DR for two years, but withdrew in 2002. The host organization was concerned that the agreement skewed the emphasis of their program too heavily toward employment-related services, which were appropriate for only about one-quarter of participants. Managers were also concerned that these services were only available to participants who were also DR clients, which resulted in the program having less flexibility in determining which individuals could participate in services they wanted. Nonetheless, the TBI Project has maintained a strong relationship with DR. The local DR office is located across the street from CCCIL, and has a counselor with a specialized TBI caseload. DR sends its clients to the TBI Project for SSI/DI benefits counseling.

Strengths and Challenges

CCCIL's service coordinator and community re-entry specialist consider their TBIs to be an asset. Their injuries legitimize their advice for participants and allow these staff to serve as role models to individuals who have recently experienced brain injuries. These staff members play central roles in participant services, and they offer participants a range of choices of support groups to attend.

The TBI Project originally had a project coordinator who devoted nearly full-time to the program. With this individual's retirement, and with reorganization of services, the TBI Project's services have started to be integrated with those of the larger independent living center. ILC staff members now sometimes provide service coordination for project participants, and project staff now serve individuals with other types of disabilities. Both staff of collaborating agencies and the program itself are somewhat concerned that the project's special qualities will be diluted by these changes.

Figure 2.2 SITE PROFILE SUMMARY: New Options, Central Coast Center For Independent Living	
Site Characteristics: <ul style="list-style-type: none"> • Host Organization • Years Providing CA TBI Project Services • CA TBI Project Funding as Percent of Organization's Budget • Service Area 	Central Coast Center for Independent Living 14 0.11% Santa Cruz County
Participants Served: Unduplicated Count of Participants PY 2003-2004	51
Number of Participants in Study Sample ^a	33
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> • Average Age • Percent Male • Percent Minority • Percent High School or Above • Percent Married • Percent with SSI/DI • Average Income • Client of Department of Rehabilitation • Percent Employed • Percent with Desire to Work 	46 years 63% male 24% minority 91% Diploma/GED or above 3% married 56% SSI or SSDI \$832.19 12% DR 6% 56%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> • Average Age at Injury • Average Time Since Injury at Intake: • Motor Vehicle Accident • Percent Substance Abuse Related • Percent with Coma • Average Duration of Coma • Percent with Limited Mobility • Percent with Pain 	33 years 14.2 years 62% 15% 36% 30 days 75% 38%
Services Provided (% Sample Receiving Each Service) at Six Months: <ul style="list-style-type: none"> • Percent Receiving Service Coordination • Special Evaluation • Living Assistance • Mental Health Services • Substance Abuse Treatment • Social/Recreational Services • Supported Employment • Employment Services • Education Services 	42% 0% 3% 0% 0% 0% 0% 3% 0%
Participant Outcomes: <ul style="list-style-type: none"> • Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> ▪ Average Percent Change in Home Score ▪ Average Percent Change in Social Score ▪ Average Percent Change in Productivity Score • Increase in Day Program Participation • Increase in Educational Status • Maintained Employment • Obtained Employment 	+0.6% +2.5% +0.3% +2.8% 6% 3% 6% 0%

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

OPTIONS, Central Coast Neurobehavior Center

The Central Coast Neurobehavior Center (CCNBC) is a nonprofit corporation established in 1984 to provide a range of services to individuals with developmental disabilities. OPTIONS offers various types of residential and community integration services, employment services, vocational assessments, and rehabilitation services. Corporate offices are located in Morro Bay; however, the TBI Project serves participants in locations throughout San Luis Obispo County. The county is predominantly rural, with suburban areas in Paso Robles, Atascadero, Morro Bay and San Luis Obispo. DMH funded OPTIONS' site in June 2003, and staff began serving participants in December of the same year. Services at the CCNBC site are built on the person-centered planning service model and have a strong vocational emphasis.

Staffing

The TBI Project has one full-time staff person, the project coordinator. She was a Qualified Mental Retardation Professional (QMRP) for a number of years, and managed all of OPTIONS' group homes for four years. She will provide intake, assessment, service planning and coordination, outreach, and community education services.

CCNBC's approach to providing the other TBI Project core services is to draw staff and expertise from the larger OPTIONS organization's various divisions. Thus, if a participant needs supported living services, staff from OPTIONS' Supported Living Services division steps in to provide the needed services. The project coordinator provides TBI training to staff from the other divisions before they begin serving participants. The site's budget includes funds for "community support specialists" to cover services provided by OPTIONS staff other than the project coordinator.

Participant Services¹

CCNBC provides services in all of the towns in its service area. The site's intake process usually starts with the project coordinator interviewing the TBI survivor's caregiver, because family members and caregivers usually initiate contact with the Project. The Project Coordinator arranges to meet with the participant to introduce the site's services, and to have the applicant sign a release for access to medical records. In part because CCNBC has recently begun serving participants, the site does not have a waiting list for services.

CCNBC created its own intake and assessment forms, combining elements required by the larger OPTIONS organization and the data items on the TBI Project's common assessment form. The project coordinator took this step in part to collect information that was more consistent with the rest of the larger organization, but also with an eye toward eventual CARF certification.

The Project Coordinator provides service coordination for all participants enrolled in the program. Because OPTIONS also operates intermediate care facilities for people with developmental disabilities (ICF/DD), the California Department of Health Services requires that a participant's residential program case manager serve as the primary service coordinator. Thus,

¹ At the time of the evaluation's site visit in February 2004, CCNBC had enrolled only six participants, so the "protocols" for providing many services were still being determined.

the project coordinator will be designated as a secondary service coordinator for participants who reside in an OPTIONS facility.

Following the person-centered planning philosophy, developing the ISP is a group process involving participants plus all of the individuals who may be involved in their lives. ISP contributors may include a residential case manager, day program staff, conservator, family member, or others. Similarly, the project coordinator will attend case conferences convened by other OPTIONS divisions on behalf of TBI Project participants. None of the current participants have been in the project long enough to have their ISPs updated, but the project coordinator anticipates that this will occur no less frequently than every six months, or at any point when participants add new goals or their circumstances change.

At the time of the evaluation's site visit, two participants were receiving community reintegration services. Staff from OPTIONS' Community Integration Services (CIS) division have crafted an individualized day program for these two individuals, which takes place entirely in the community. With the CIS staff person, the participants ride the bus, run errands, visit the library, or get coffee. At the same time that the participants are getting out and about, the CIS staff provide cuing, reminders, and other assistance as needed.

Only one TBI Project participant was involved in vocational services at the time of the evaluation's site visit. This individual was working part-time, with employment supports, in a UPS store in Paso Robles that the host organization had recently purchased. CCNBC planned to expand prevocational and vocational services at this location.

Funding

Currently, the DMH grant and \$30,000 in matching funds from the host organization are the only sources of funding for the site. These funds total \$180,000 per year.

Collaboration and Community Education

The site signed an MOU with Coast Caregivers Resource Center for outreach to caregivers and for caregiver education. The project coordinator also participates monthly in a job developers' collaborative held at DR.

CCNBC's community education efforts were limited at the time of the evaluation site visit, focusing primarily on outreach to the local Regional Center and the job developers' collaborative. Because the site's host organization provides such a comprehensive range of services, CCNBC has probably spent less time on outreach at start-up than the other two sites funded most recently.

OPTIONS currently provides several vocational services as a DR vendor, and the project coordinator meets weekly with a DR counselor from the local office. At the time of the evaluation's site visit, CCNBC was in negotiations with DR to be included under the DMH/DR interagency cooperative agreement. CCNBC plans to offer work adjustment services at the OPTIONS-owned UPS store in Paso Robles through the cooperative agreement. Senior OPTIONS staff noted that, even though the organization has had a long-standing positive

relationship with DR, the process of establishing the cooperative agreement has been a rocky one and has taken much longer than they had anticipated.

Strengths and Challenges

The site's service design is flexible and CCNBC brings to the TBI Project the resources of the larger OPTIONS organization. As a result, CCNBC can offer participants a depth of services that would not be available in a project of similar size operating on its own. The TBI Project is able to access the services of experienced staff on a part-time basis, individuals who might not be available to the site if it tried to hire them on a part-time basis independent from the rest of OPTIONS. Site staff have a good working relationship with staff in the local DR office, in part because of the reputation of the larger organization.

The previous experience of CCNBC staff has been in very structured services systems, such that the TBI Project's flexibility and lack of policies made the start-up process somewhat of a challenge. Staff would have liked more support, information sharing, and mentoring from the long-standing TBI Project sites to facilitate the process of starting up site services.

Figure 2.3 SITE PROFILE SUMMARY: OPTIONS, Central Coast Neurobehavior Center	
Site Characteristics: <ul style="list-style-type: none"> Host Organization Years Providing CA TBI Project Services CA TBI Project Funding as Percent of Organization's Budget Service Area 	Central Coast Neurobehavior Center 1 5% San Luis Obispo and Santa Barbara Counties
Participants Served: Unduplicated Count of Participants PY 2003-2004	41
Number of Participants in Study Sample ^a	25
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> Average Age Percent Male Percent Minority Percent High School or Above Percent Married Percent with SSI/DI Average Income Client of Department of Rehabilitation Percent Employed Percent with Desire to Work 	40 years 84% male 8% minority 88% Diploma/GED or above 20% married 63% SSI or SSDI \$1093.75 48% DR 8% 88%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> Average Age at Injury Average Time Since Injury at Intake Motor Vehicle Accident Percent Substance Abuse Related Percent with Coma Average Duration of Coma Percent with Limited Mobility Percent with Pain 	28 years 11.7 years 76% 24% 29% 71 days 67% 25%
Services Provided (% Sample Receiving Each Service) at Six Months: <ul style="list-style-type: none"> Percent Receiving Service Coordination Special Evaluation Living Assistance Mental Health Services Substance Abuse Treatment Social/Recreational Services Supported Employment Employment Services Education Services 	32% 8% 12% 8% 0% 8% 0% 20% 4%
Participant Outcomes: <ul style="list-style-type: none"> Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> Average Percent Change in Home Score Average Percent Change in Social Score Average Percent Change in Productivity Score Increase in Day Program Participation Increase in Educational Status Maintained Employment Obtained Employment 	+7.8% 0.0% +6.9% +45.0% 0% 0% 8% 33%

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

Making Headway, Inc.

Making Headway is a small nonprofit organization that provides post-acute services for people with traumatic brain injury. Its founders had provided services to individuals with brain injuries for two decades prior to incorporating in 1999. DMH awarded a contract for the organization's local "System of Care Project" in June 2003, and the site began serving participants in December 2003. Making Headway is located in Eureka and primarily serves Humboldt County, although the site is also committed to providing community education services to Del Norte and Mendocino Counties. The service area is rural, behind the "redwood curtain," a three to five hour drive from any other city of any size. The TBI Project's service model is one of therapeutically-based case management.

Staffing

Together, Headway's four staff work just over two full-time equivalents (FTE). The program director has past experience supervising a day respite program for adults and is employed by the grant .68 FTE. In addition to overseeing site operations, she provides service coordination. Headway's case manager is a TBI survivor with a medical background. She works .75 FTE. The site's budget also covers the organization's executive director at half time; she is a registered nurse and a marriage and family therapist with 20 years' experience working with TBI survivors. The fourth site staff member is the administrative assistant, who devotes .38 FTE to the TBI Project.

Participant Services

Headway's program director completes all intakes, although assessments may be done either by the case manager or the program director. Staff use the TBI Project common assessment form. As one of the newer sites, Headway does not have a waiting list for services. After the participant's assessment is completed, staff schedule a follow-up meeting with the individual to develop an ISP. The initial service plan is limited to two major goals to help participants stay focused on moving forward. The emphasis of the ISP is on connecting the participant with other community-based services. This can be a major challenge in a predominantly rural area with small communities. While many services are available in Eureka, transportation to Eureka from other parts of the county can be problematic. The site's case manager lives in the southern part of Humboldt County and will sometimes meet participants there, at their homes or at a coffee shop.

Both the program director and the case manager provide service coordination, the site's biggest service emphasis. During participants' active phase of services, they meet with staff regularly, on average twice per month. Throughout the process, Headway staff emphasize both supporting participants and encouraging their autonomy.

Staff primarily provide supported living services in participants' homes. This type of assistance may include providing memory tools or strategies for organization, cooking, linking participants to IHSS, supervising care providers, and money and medication management.

In addition to referring participants to community reintegration services in the community, staff provide services such as accompanying participants—and providing transportation—to appointments with doctors, attorneys, and the court. Staff members also assist participants in looking for housing.

Headway's services strongly emphasize support groups because many participants have few opportunities for socialization. The groups tend to develop a cohesiveness, and often pick names for themselves. For example, one group has named itself the "Headbangers." Staff noted that as the TBI Project has expanded, new participants coming in tend to be older, more likely to be female, and have different levels of functioning than individuals who participate in long-standing groups. As a result, the site has expanded the number of support groups available to participants. A newer group, called "Upward Bound," is held at St. Joseph's Hospital and, compared to some other groups, has more focus on activities, jobs, attending school, and moving forward with their lives. Another group being developed in response to the needs of more recent participants is a parenting group for mothers with TBI.

Very few of Headway's participants were interested in employment at the time of the evaluation visit, and only six were DR clients. Site staff work with the DR counselor in serving these participants. The organization is interested in being included under the DMH/DR cooperative agreement, however, staff stated that many Headway participants have been in crisis during their time in the program, and need to "put out fires" before they can think about work. Thus, the site has not pursued participation in the agreement at this time.

At the time of the evaluation's site visit, staff were conducting a needs assessment among participants' family members. The results of this survey will be used to determine the content of an upcoming class for the TBI Caregiver Education and Support Network.

Funding

Other than the \$30,000 match from the host organization, the DMH contract budget of \$150,000 per year is the only source of funding for the site. This amount represents over half of the organization's annual budget. This site has used a subcontract with the local Linkages project to access Medicaid Targeted Case Management (TCM) funds, however that subcontract ended in FY03-04.

Collaboration and Community Education

Headway has cooperative agreements with four local agencies for provision of services, and serves as a vendor for another. The site's agreement with the Redwood Caregiver Resource Center covers conducting a caregiver support group for participants' families. The second cooperative agreement is with St. Joseph Hospital to conduct a regular support group for vocationally-inclined TBI survivors. The Senior Resource Center provides space for support group meetings under a third agreement. The fourth cooperative agreement is with the local school district to operate a class for TBI survivors through its adult school. Headway staff gave input into the design of the classes, and have occasionally supplemented the curriculum by supplying extra teachers for the class. Site staff meet monthly with the program's administrator and instructor to discuss the implementation and progress of the class, as well as any potential referrals to the program.

Headway is a vendor for the local Regional Center for participants injured prior to age 18. In addition, TBI Project staff work closely with the county mental health agency in serving individuals who have dual diagnoses of TBI and mental illness.

Headway staff have done both outreach and community education across the community, including providing training at the local One-Stop Career Center and the district attorney's office. Staff have held seminars for law enforcement, other case managers, nurses, IHSS providers, and clinicians. The TBI Project has allowed the site to significantly increase its community presence.

Strengths and Challenges

Staff of agencies that collaborate with Headway consider the site's community education efforts to be an important strength of the TBI Project, and reported that these services have had a large impact on Humboldt County. Collaborators also value the high quality of the TBI Project's services, as well as the fact that the site offers participants the personal therapy they need for growth. Staff members respond quickly to needs as they arise, and offer participants creative supports and compensatory strategies.

Making Headway's driving force is its heart and desire to help; however, these motivating factors sometimes undermine the business needs of the organization. Financial stability, including securing enough funding for the services staff provide, has been the site's biggest challenge. The organization's Board has participated in Directors' training through the Humboldt Foundation, and is encouraging staff to learn how to maximize fiscal efficiency without sacrificing the project's level of caring for participants.

Figure 2.4 SITE PROFILE SUMMARY: Making Headway, Inc.	
Site Characteristics: <ul style="list-style-type: none"> • Host Organization • Years Providing CA TBI Project Services • CA TBI Project Funding as Percent of Organization's Budget • Service Area 	Making Headway 1 57% Humboldt, Del Norte, and Mendocino Counties
Participants Served: Unduplicated Count of Participants PY 2003-2004	27
Number of Participants in Study Sample ^a	11
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> • Average Age • Percent Male • Percent Minority • Percent High School or Above • Percent Married • Percent with SSI/DI • Average Income • Client of Department of Rehabilitation • Percent Employed • Percent with Desire to Work 	41 years 73% male 8% minority 82% Diploma/GED or above 9% married 40% SSI or SSDI \$749.33 10% DR 27% 73%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> • Average Age at Injury • Average Time Since Injury at Intake • Motor Vehicle Accident • Percent Substance Abuse Related • Percent with Coma • Average Duration of Coma • Percent with Limited Mobility • Percent with Pain 	27 years 13.4 years 70% 9% 46% 22 days 22% 33%
Services Provided (% Sample Receiving Each Service) at Six Months:^b <ul style="list-style-type: none"> • Percent Receiving Service Coordination • Special Evaluation • Living Assistance • Mental Health Services • Substance Abuse Treatment • Social/Recreational Services • Supported Employment • Employment Services • Education Services 	
Participant Outcomes: <ul style="list-style-type: none"> • Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> ▪ Average Percent Change in Home Score ▪ Average Percent Change in Social Score ▪ Average Percent Change in Productivity Score • Increase in Day Program Participation • Increase in Educational Status • Maintained Employment • Obtained Employment 	

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

^b Making Headway had been providing services for too short a period to conduct any six-month assessments.

Mercy General Hospital Coordinated Care Project

Mercy's Coordinated Care Project is co-located with Mercy Outpatient Rehabilitation Center in Roseville, a part of Catholic Healthcare West (CHW). CHW operates 41 acute care hospitals, as well as skilled nursing facilities, outpatient rehabilitation clinics, and other health clinics throughout California, Arizona, and Nevada. In addition to the TBI Project, the Roseville Outpatient Rehabilitation Center offers neuro-pediatric and orthopedic rehabilitation programs. The TBI Project serves a mixture of urban, suburban, and rural communities in Sacramento, Yolo, and Placer Counties. One of the four original TBI Projects first implemented in 1990, Mercy's program is built on a medical service model and incorporates the provision of neuropsychological services, as well as speech, occupational, and physical therapies.

Staffing

The site has five staff members, who together comprise a total of 2.7 FTE. Mercy's project director is also the site's service coordinator and its only full-time employee. A physical therapist by training, she has worked for the TBI Project since July 2000. The supervisor of the Outpatient Rehabilitation Center provides administrative oversight for the TBI Project (.20 FTE). A speech pathologist, she was involved in writing Mercy's original proposal for the TBI Project, and has served as interim project director several times over the years.

The site's neuropsychologist devotes 40% of her time to the project, assessing participants, providing therapy, and facilitating the Bridges support group. Other staff members work varying numbers of hours per week for the project, depending upon the need for their assistance. This strategy allows the program to provide speech, occupational, and physical therapies, even though funding is not available to hire therapists on a full-time basis. A speech therapist runs the Life Skills course, helps facilitate the Bridges group, and serves as job coach for participants who hold volunteer positions within Mercy. The occupational therapist and physical therapist also help facilitate the Bridges group. In addition, all three therapists are involved in the participant assessment process.

Participant Services

Both the service coordinator and the neuropsychologist interview applicants during the intake process. The site does not have a waiting list for services. Once the applicant becomes a participant, the service coordinator creates a formal ISP, which the participant signs.

The site offers four program components, each tailored to TBI survivors at a slightly different point of recovery. First, Mercy provides short-term outpatient service coordination and/or neuropsychological services for TBI survivors receiving outpatient rehabilitation therapies through the Roseville Outpatient Rehabilitation Center; typically these individuals enter the program about two months post-injury. Participants may see the neuropsychologist, and/or receive occupational, physical, and/or speech therapies, in addition to service coordination and education about TBI for both participants and their families.

Second, Mercy intermittently offers a life skills course, targeting participants who are approximately one year post-injury. This ten-week course is generally offered once or twice per year depending upon demand, and meets four times a week for two hours per day. Curriculum

covers TBI education, health and fitness, time management, communication, community reintegration, adjustment/adaptation/problem-solving, organization, and instrumental activities of daily living. At the time of the evaluation's site visit, Mercy was not offering the life skills course because the site had not received enough appropriate referrals for the class.

Third, the site started the Bridges group in Summer 2003 for individuals who are between six and 12 months post-injury. Bridges meets for two and a half hours per week, with curricula varying from week to week. One week's activities focus on support group and physical fitness (led by the neuropsychologist and physical therapist, respectively), while the next week, activities are related to recreation and leisure, organization, cognitive development, and community reintegration (led by the occupational and speech therapist). Unlike the life skills course, Bridges has a rolling enrollment policy, and participants can stay in the group as long as they are benefiting from participation.

Finally, Mercy provides vocational services under DMH's interagency cooperative agreement with DR. Under the agreement, DR and Mercy share referrals and use a joint referral form. Individuals must meet both DR and TBI Project eligibility criteria to be served through the cooperative agreement. Mercy provides vocational assessment services and Personal Vocational and Social Adjustment services (PVSA) to DR clients with TBI. Once the individual is ready to enter employment, DR refers the participant to Crossroads Employment Services for supported employment or help in finding a competitive placement. Crossroads is a nonprofit organization that provides employment and training services to people with disabilities in the Sacramento area. Mercy staff meet bimonthly with their designated DR counselor and staff from Crossroads. The agenda for these meetings alternates weekly between discussing participants currently working with Crossroads, and individuals who are moving toward receiving vocational services through the cooperative agreement.

Funding

Catholic Healthcare West has a strong commitment to the TBI Project since the program fits well within its overall organizational mission. The host organization subsidizes the grant with at least 100% match of in-kind services each year (though a lesser amount is reflected in the site's DMH contract budget). Nonetheless, the sustainability of the match is an issue revisited every year when Mercy signs its contract and, over time, Catholic Healthcare West has reduced the amount of its match for its own financial health.

The cooperative agreement between DMH and DR is another source of funding for the Mercy sites. Of the site's \$150,000 contract budget, \$30,000 is used as matching funds for the cooperative agreement with DR. This match secures another \$114,000 in funds for vocational services. Overall, including the host organization's match, Mercy's annual budget is \$352,701.

Collaboration and Community Education

Since 2000, Mercy has served as the lead agency for the Sacramento TBI Network. Consisting of about 20 providers of services to individuals with TBI, the Network is working to maximize their collective impact, facilitating referrals between the groups, building relationships, and providing public and professional TBI education. A core group of about eight organizations meets

quarterly. The Network recently produced a resource guide for relevant services available in the area.

In addition to its work with the Network, Mercy staff provide in-service training to staff of its host organization in general, and trauma unit staff in particular. Staff members have also provided community education to local police departments, community service providers, state agencies, and disability attorneys.

Mercy is the only one of the original four grantees to continue providing vocational services under the interagency cooperative agreement. Staff considered withdrawing from the agreement when DR managers proposed using several different counselors to serve the TBI Project participants instead of just one. The site's experience had shown that use of a specialist DR counselor was critical to participant success, and Mercy was able to convince DR to designate a single counselor to serve all clients who participate in the TBI Project. The service process now operates more smoothly than it did in previous years.

Strengths and Challenges

Mercy's staff have a "passion for the work" of assisting TBI survivors to live more independently. Staff have a wealth of experience, especially with hard-to-treat patients. This is important in bringing new staff on, according to interview respondents, because experienced staff can teach new staff how to have some successes in working with participants, which lessens burnout and turnover.

The TBI Project benefits from the commitment of Mercy Healthcare, Sacramento to this program. Nonetheless, both administrators from Catholic Healthcare West and Mercy staff observed that, even with funding from the cooperative agreement, their current level of funding is not adequate to cover participant services, outreach, and community education. They noted, however, that limited funding has fostered creativity in maximizing funds in order to serve TBI survivors.

Figure 2.5 SITE PROFILE SUMMARY: Mercy General Hospital Coordinated Care Project	
Site Characteristics: <ul style="list-style-type: none"> Host Organization Years Providing CA TBI Project Services CA TBI Project Funding as Percent of Organization's Budget Service Area 	Catholic Healthcare West 14 0.1% Sacramento, Placer, and Yolo Counties
Participants Served: Unduplicated Count of Participants PY 2003-2004	42
Number of Participants in Study Sample ^a	46
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> Average Age Percent Male Percent Minority Percent High School or Above Percent Married Percent with SSI/DI Average Income Client of Department of Rehabilitation Percent Employed Percent with Desire to Work 	37 years 74% male 15% minority 85% Diploma/GED or above 26% married 46% SSI or SSDI N/A 7% DR 9% 74%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> Average Age at Injury Average Time Since Injury at Intake Motor Vehicle Accident Percent Substance Abuse Related Percent with Coma Average Duration of Coma Percent with Limited Mobility Percent with Pain 	35 years 1.9 years 74% 42% 61% 20 days 31% 31%
Services Provided (% Sample Receiving Each Service) at Six Months: <ul style="list-style-type: none"> Percent Receiving Service Coordination Special Evaluation Living Assistance Mental Health Services Substance Abuse Treatment Social/Recreational Services Supported Employment Employment Services Education Services 	50% 9% 2% 4% 2% 13% 0% 2% 0%
Participant Outcomes: <ul style="list-style-type: none"> Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> Average Percent Change in Home Score Average Percent Change in Social Score Average Percent Change in Productivity Score Increase in Day Program Participation Increase in Educational Status Maintained Employment Obtained Employment 	+38.7% +89.4% +14.7% +94.1% 7% 4% 9% 56%

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

St. Jude Brain Injury Network

Funded in 1990 as one of the four original TBI Project sites, the St. Jude Brain Injury Network (BIN) is a program of the St. Jude Medical Center. The Medical Center is part of the St. Joseph Health System (SJHS) which includes 14 hospitals and three home health agencies, as well as hospice care, outpatient services, skilled nursing facilities, and physician organizations. The site's office is co-located with the Orange Caregiver Resource Center in Fullerton. St. Jude serves Orange County, a dense urban and suburban area, with expensive housing and a relatively poor public transportation system. St. Jude BIN's service model is based on intensive case management.

Staffing

St. Jude's TBI Project has four staff members, including the project director and a service coordinator who both work full-time, and two part-time administrative support staff. The project director has an extensive background in employment development, while the service coordinator has substantial experience working with TBI survivors in the St. Jude Medical Center Rehabilitation Department, including providing life skills training and running a head injury day program.

A hallmark of St. Jude's service model is that all staff work with all participants. This includes intake, assessment, service planning, service coordination, advocacy, supported living, and community reintegration services.

Participant Services

TBI Project staff complete intake forms on all TBI survivors who contact the site. Because St. Jude currently has a waiting list for enrollment, the decision about whether an applicant becomes a participant depends on the site's total caseload at any given time. The staff are in the process of identifying which long-term participants have completed project services and terminating them in order to reduce or eliminate the waiting list.

Site staff use the TBI Project's common assessment form to complete participants' initial (and subsequent) assessments. Staff generally begin working to develop the ISP as soon as the assessment is completed, building on the goals and/or needs identified during the assessment. Staff members update ISPs every three to six months, depending on the progress participants are making toward their goals.

Since multiple staff members may serve each participant, staff rely on notes in participants' case files in order to stay up to date on each individual while providing ongoing service coordination. In addition, staff members provide formal updates during regular monthly staff meetings as well as more informal exchanges of information as needed.

St. Jude staff identified much of what they do as advocacy—assisting participants in dealing with red tape associated with the housing authority, Social Security, and other benefit systems. The most frequent community reintegration services they provide are housing assistance, referring or

helping participants apply for an acquired brain injury program at one of the local community colleges, referrals to psychological counseling, and helping participants access transportation (e.g., bus vouchers or paratransit).

In response to participants' need for socialization (community reintegration), staff began putting together a regular calendar of local events. The calendar includes both low and no cost activities, and is sent out monthly to all participants.

The project addresses most supported living services via referral to other agencies. Staff directly provide a few supported living services, such as dealing with landlords and helping participants to set up systems for handling paperwork.

St. Jude staff provide limited vocational supports; they also refer participants to DR, the Regional Occupational Program (ROP), and sometimes to the local One-Stop Career Center. Staff help participants with interviewing skills, assist with developing resumes, and encourage participants in conducting their job search.

The site does not offer support groups because these already exist elsewhere in the community. The project director attends one of the local support groups held twice a month at Saddleback Hospital. In addition, at the time of the evaluation's site visit, a group of St. Jude participants were planning to start their own peer support group.

Funding

The Orange Caregiver Resource Center provides both office space at a discounted rate and administrative oversight of the TBI Project as an in-kind match to DMH contract funds. St. Jude Medical Center also provides an in-kind match of computer, financial, and legal services. These, plus the DMH contract, are the site's only funding. In total, St. Jude's annual budget is \$182,487.

Collaboration and Community Education

St. Jude's collaborative efforts in the community include membership in the Anaheim Human Services Network. The site signed an MOU with the Orange County Volunteer Center for community reintegration services. Under the terms of this agreement, the Center assists in finding participants volunteer job placements. The site also contracts with the Orange Caregiver Resource Center for family support services.

The project director does community outreach, making presentations to other organizations about the TBI Project and its services. She also serves on the boards of directors of several other agencies, including the Orange County Homeless Coalition, which consists of over 100 service agencies in the area. In addition, she helped establish a nonprofit organization that manages a 24-unit apartment building for people with TBI and other disabilities. Several St. Jude participants live there.

Once per month, the project director travels to Coastline Community College to attend its cognitive retraining class. This visit is an opportunity to establish relationships with the TBI survivors attending the class. In addition, she gives presentations on TBI to staff of St. Jude

Medical Center in collaboration with a neuropsychologist, and employment and training workshops at other human service agencies. Further, one of the service coordinators has given presentations through a “speakers’ bureau” organized by the Volunteer Center.

Strengths and Challenges

The St. Jude BIN has a good knowledge of the needs of TBI survivors, and provides intensive service coordination services. One of its strengths is advocacy on behalf of participants with Social Security and other programs. Staff from collaborating agencies commented that the site has a large impact on the local community through its workshops, provision of a regularly updated directory of services, and collaboration with a broad range of agencies throughout the county.

One of the challenges that the site faces is the fact that it carries the St. Jude name but receives minimal support from the host organization. For example, the TBI Project was not included in the Medical Center’s promotional materials and was not mentioned on the host organization’s web page until very recently. A related dilemma is that the host organization is apprehensive of the site doing its own fund-raising for fear that this would divert donations from the Medical Center.

Figure 2.6 SITE PROFILE SUMMARY: St. Jude Brain Injury Network	
Site Characteristics: <ul style="list-style-type: none"> • Host Organization • Years Providing CA TBI Project Services • CA TBI Project Funding as Percent of Organization's Budget • Service Area 	St. Jude Medical Center 14 100% Orange County
Participants Served: Unduplicated Count of Participants PY 2003-2004	86
Number of Participants in Study Sample ^a	19
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> • Average Age • Percent Male • Percent Minority • Percent High School or Above • Percent Married • Percent with SSI/DI • Average Income* • Client of Department of Rehabilitation • Percent Employed • Percent with Desire to Work 	36 years 58% male 16% minority 95% Diploma/GED or above 16% married 27% SSI or SSDI \$810.00 11% DR 37% 94%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> • Average Age at Injury • Average Time Since Injury at Intake • Motor Vehicle Accident • Percent Substance Abuse Related • Percent with Coma • Average Duration of Coma • Percent with Limited Mobility • Percent with Pain 	28 years 7.9 years 73% 39% 68% 15 days 60% 40%
Services Provided (% Sample Receiving Each Service) at Six Months: <ul style="list-style-type: none"> • Percent Receiving Service Coordination • Special Evaluation • Living Assistance • Mental Health Services • Substance Abuse Treatment • Social/Recreational Services • Supported Employment • Employment Services • Education Services 	42% 5% 5% 0% 0% 0% 0% 5% 0%
Participant Outcomes: <ul style="list-style-type: none"> • Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> ▪ Average Percent Change in Home Score ▪ Average Percent Change in Social Score ▪ Average Percent Change in Productivity Score • Increase in Day Program Participation • Increase in Educational Status • Maintained Employment • Obtained Employment 	+63.9% +130.8% +93.0% +7.9% 0% 5% 37% 13%

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

San Francisco TBI Network, Janet Pomeroy Center

The San Francisco Traumatic Brain Injury Network was funded in late 2001 as a collaborative project between the Janet Pomeroy Center (JPC) and the Rehabilitation Department of St. Mary's Medical Center. Founded in 1952, the Janet Pomeroy Center (formerly Recreation Center for the Handicapped) is a nonprofit organization that provides therapeutic recreation, vocational rehabilitation, transportation, and respite care services to children, adults, and seniors with developmental disabilities and acquired brain injuries. St. Mary's is a part of Catholic Healthcare West, a large nonprofit hospital-based healthcare system. The Medical Center's Rehabilitation Department includes specialized services for brain injury survivors, provided by multicultural and multidisciplinary staff. The TBI Project serves the City and County of San Francisco, a relatively small and dense urban area. The site's service model combines service coordination/case management, prevocational, and vocational support services.

Staffing

Pomeroy has five full-time staff, including the project supervisor, two service coordinators, and two employment specialists. None have clinical backgrounds, although the project supervisor holds a Master's degree in social welfare, and one of the service coordinators has a Bachelor's degree in the same discipline. Staff members are administratively located in two different parts of the larger JPC organization, depending upon their function. The project supervisor and service coordinators work under the organization's director of programs. The site's employment specialists, on the other hand, report to the JPC director of rehabilitation.

Participant Services

Pomeroy offers services at two sites—the JPC headquarters and St. Mary's Ben Berman Outpatient Rehabilitation Program in downtown San Francisco. The service coordinator stationed at St. Mary's tends to work with participants who have recently completed rehabilitation, usually about six months post-injury, while the other service coordinator works with participants who experienced their injuries much longer ago, and who have dual diagnoses of TBI and psychiatric disabilities.

The site does not have a waiting list for services. Participants enrolling in the TBI Project complete a two-part intake process that involves filling out consent forms and other paperwork with one of the service coordinators, and then meeting with the project supervisor. The service coordinators complete the assessment over the course of two meetings with the participant. Generally, the ISP is also completed at the second assessment meeting. Staff keep ISP goals very focused, and usually only include in the ISP one step at a time toward a major goal. In addition, the ISPs are updated each time the service coordinator and participant meet, so plans are updated or new plans opened fairly frequently.

The service coordinators devote much of their efforts to providing participants with various types of supportive services related to either community reintegration needs or supported living needs. Because of the high cost of real estate in the San Francisco Bay Area, housing is frequently an issue among participants. Staff also assist participants with SSI appeals, enrolling in Medicare, and securing IHSS. The most frequently needed supported living service is help with budgeting and money management.

Pomeroy offers a support group that meets twice per month at St. Mary's. A neuropsychologist who regularly works with the site facilitates the support group, while the service coordinators alternate in attending the group. The service coordinators secure a guest speaker when the regular facilitator is not available. Pomeroy staff noted that attending the support group is one means of assisting individuals with recent injuries to acknowledge that they have TBI, which they are often reluctant to do.

Pomeroy provides vocational services directly, using funds from the interagency cooperative agreement between DMH and DR. A single DR counselor is responsible for all of the TBI Project's participants. Service coordinators work with participants who are interested in employment to help them identify career goals and apply for DR services. At this point, they hand off participants to the site's employment specialists. To ensure that the participant's support needs continue to be met, the service coordinators continue to attend team meetings with the participant, employment specialists, and DR counselor every other week.

The site's employment specialists complete a vocational assessment that is shared with the individual's DR counselor. The participant often moves into a volunteer job/situational assessment next, supported on site as needed by the employment specialist. Pomeroy's employment specialists are responsible for finding volunteer job opportunities, often relying on their relationships with St. Mary's and St. Francis' hospitals to identify placements. Once participants and their employment specialists decide that they are ready for work, they convene a team meeting to discuss job goals and next steps. At this point, the DR counselor refers the participant to another vocational program—often Pomeroy's own Employment Program—for help with placement. The site's employment specialists often continue to provide support with identifying job leads or practicing interview skills.

Funding

Both JPC and St. Mary's provide in-kind services as matching funds for the site's DMH contract. For example, St. Mary's provides an office for one of the site's service coordinators as part of the in-kind match.

Pomeroy's funding comes primarily from the DMH contract and the DMH/DR interagency agreement. Of the site's \$150,000 annual contract budget, \$30,000 is used as matching funds for the cooperative agreement with DR. This match secures another \$114,000 in funds for vocational services. Overall, including the host organization match, the site's annual budget is \$324,751.

Collaboration and Community Education

As the site was in its startup phase, the lead service coordinator focused on outreach to identify the service programs that participants would be most likely to use. She took care to establish strong relationships with staff at St. Mary's, the local independent living center, and the Family Caregiver Alliance. As the number of Pomeroy participants has grown, however, staff no longer have time for outreach.

The DMH/DR interagency agreement includes provisions for Pomeroy staff to provide TBI education to DR staff, and the project supervisor was planning such a session at the time of the evaluation's site visit. The agreement also serves as a means to sustain collaboration with DR, since the employment specialists and service coordinators meet with the DR counselor every other week for team meetings about individual participants. In addition, the project supervisor and the DR supervisor meet quarterly to address any issues that have arisen in implementing vocational services for participants. One result of these administration meetings was a written protocol clarifying the joint delivery of services by DR and Pomeroy.

Strengths and Challenges

Pomeroy staff offer participant-focused services with a personal approach. Staff are available and reliable, and establish good, trusting relationships with participants.² Nonetheless, the service coordinators, in particular, were proud that they were teaching and empowering participants to do things independently, giving them more control over their lives.

While Pomeroy staff knew that they would be serving TBI survivors who were most in need, they did not anticipate serving the number of homeless participants who have enrolled in the project. The service coordinators had to adjust both their expectations, and their community resources, to accommodate the needs of these participants.

² Results of the Participant Satisfaction Survey confirmed these observations. One of the service coordinators left the project, and several participants expressed a deep sense of betrayal that he was gone.

Figure 2.7 SITE PROFILE SUMMARY: San Francisco TBI Network, Janet Pomeroy Center	
Site Characteristics: <ul style="list-style-type: none"> Host Organization Years Providing CA TBI Project Services CA TBI Project Funding as Percent of Organization's Budget Service Area 	Janet Pomeroy Center 3 6% City and County of San Francisco
Participants Served: Unduplicated Count of Participants PY 2003-2004	63
Number of Participants in Study Sample ^a	26
Demographics of Study Sample at Intake: <ul style="list-style-type: none"> Average Age Percent Male Percent Minority Percent High School or Above Percent Married Percent with SSI/DI Average Income* Client of Department of Rehabilitation Percent Employed Percent with Desire to Work 	42 years 73% male 35% minority 92% Diploma/GED or above 4% married 65% SSI or SSDI \$1054.00 35% DR 19% 100%
Injury Characteristics of Study Sample: <ul style="list-style-type: none"> Average Age at Injury Average Time Since Injury at Intake Motor Vehicle Accident Percent Substance Abuse Related Percent with Coma Average Duration of Coma Percent with Limited Mobility Percent with Pain 	29 years 15.4 years 46% 27% 46% 28 days 71% 14%
Services Provided (% Sample Receiving Each Service) at Six Months: <ul style="list-style-type: none"> Percent Receiving Service Coordination Special Evaluation Living Assistance Mental Health Services Substance Abuse Treatment Social/Recreational Services Supported Employment Employment Services Education Services 	73% 15% 12% 35% 4% 12% 16% 27% 12%
Participant Outcomes: <ul style="list-style-type: none"> Average Percent Change in Total CIQ Score for Study Sample at Six Months <ul style="list-style-type: none"> Average Percent Change in Home Score Average Percent Change in Social Score Average Percent Change in Productivity Score Increase in Day Program Participation Increase in Educational Status Maintained Employment Obtained Employment 	+17.1% +24.5% +18.3% - 0.8% 39% 8% 12% 0%

^a The study sample consists of participants who enrolled between February 2003 and June 2004.

The next chapter describes the TBI Project's participants in more detail than is presented in the profiles, above.

3. Characteristics of TBI Project Participants Enrolled in Fiscal Year 2003 – 2004

As a group, the TBI Project sites served a total of 610 participants in Fiscal Year 2003-2004 (FY03-04). The evaluation sample was defined as all participants who first enrolled in the program between February 1, 2003 and June 30, 2004. These individuals represent the first group of participants for whom the sites completed the Community Integration Questionnaire (CIQ), the evaluation's tool for assessing the degree of participant community reintegration. The resulting sample consisted of 213 participants. All individuals in the study sample were participants in FY03-04, although only 155 had their initial assessment and first service plan completed during this fiscal year. The other 58 participants first received Project services in FY02-03.

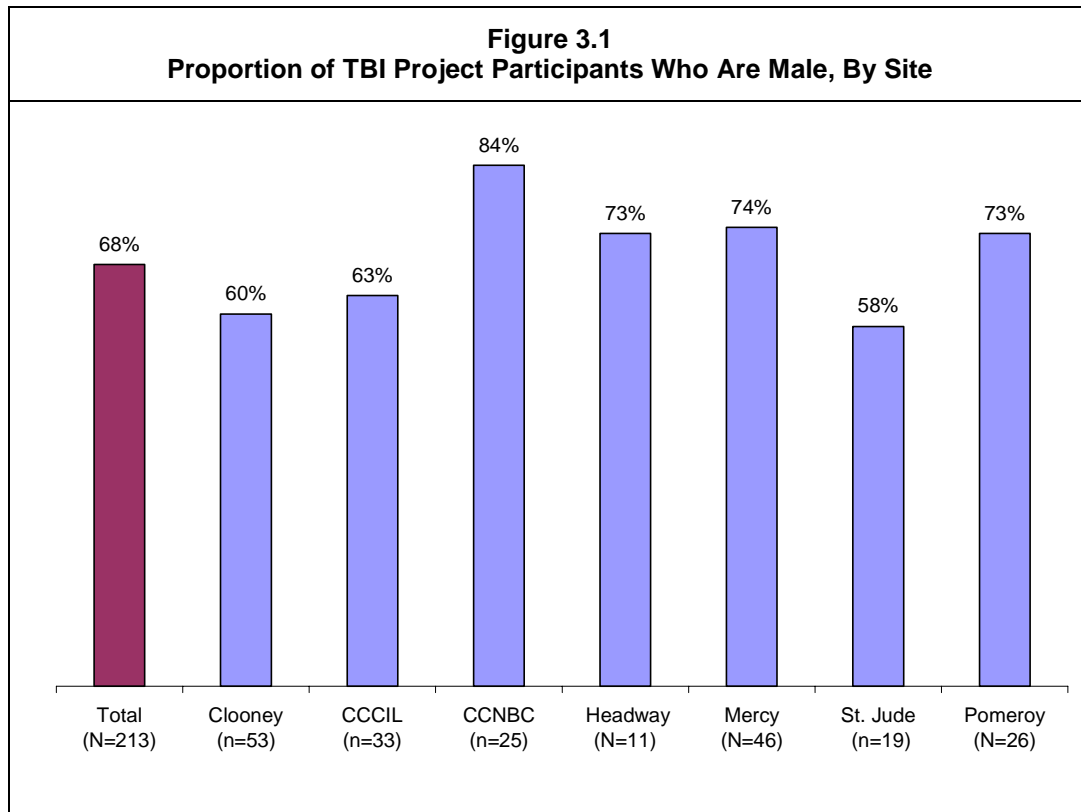
Using the TBI Project's assessment form, we collected data on personal characteristics, service use, and outcomes for the 213 participants in the evaluation sample. This chapter describes the findings from analysis of these data. According to staff of the TBI Project sites, the evaluation sample was fairly representative of all of the participants they serve, with a few exceptions that are noted below. First, we discuss personal demographic characteristics at intake, then characteristics related to participants' brain injury. Next, we describe participants' vocational status at intake, and then summarize their presenting needs when they enrolled in the project. Tables displaying more detailed information on participants in the study sample for all seven of the TBI Project sites are available in Appendix A-1: Supplemental Tables on Evaluation Sample.

Demographic Characteristics

The typical TBI Project participant is a 41-year old single white male who has attended some college, receives SSI or SSDI, and lives either alone or with a family member. Aside from this broad generalization, the data show that participants varied widely across a number of characteristics.

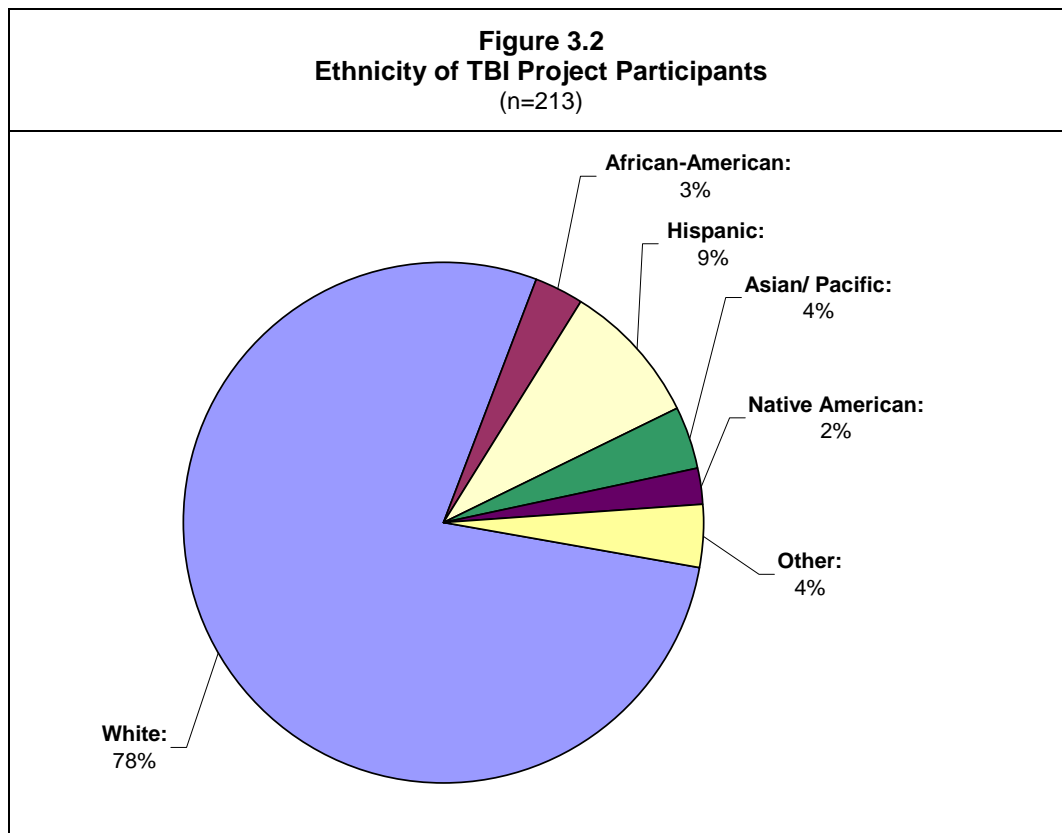
As a group, participants in the study sample ranged in age from 18 to 79 years at the time of intake, and, on average, were 41 years old. The average age across the TBI Project sites was fairly consistent; CCCIL's participants were the oldest with an average age of 46, while the youngest group of participants was from St. Jude, with an average age of 36.

Two-thirds of participants were male across all of the sites. As Figure 3.1 illustrates, the sites varied substantially in the proportion of males and females they served. A large majority of CCNBC participants were male (84%), compared to just over half (58%) of St. Jude participants.



Despite the efforts of TBI Project staff to increase the diversity of the program's clientele to reflect the ethnic diversity of the state's overall population, more than three-quarters of the participants were white (78%). Figure 3.2 shows that relatively small proportions of participants were Hispanic (9%, compared to 32%¹ in the state as a whole), Asian (4% vs. 11% in the state), black or African American (3% compared to 7% in the state), or "other" (4% vs. 15% in the state). While American Indians or Alaskan Natives represent only 1% of the state's population, 2% of TBI Project participants were Native American (although with this sample size, that difference is not significant).

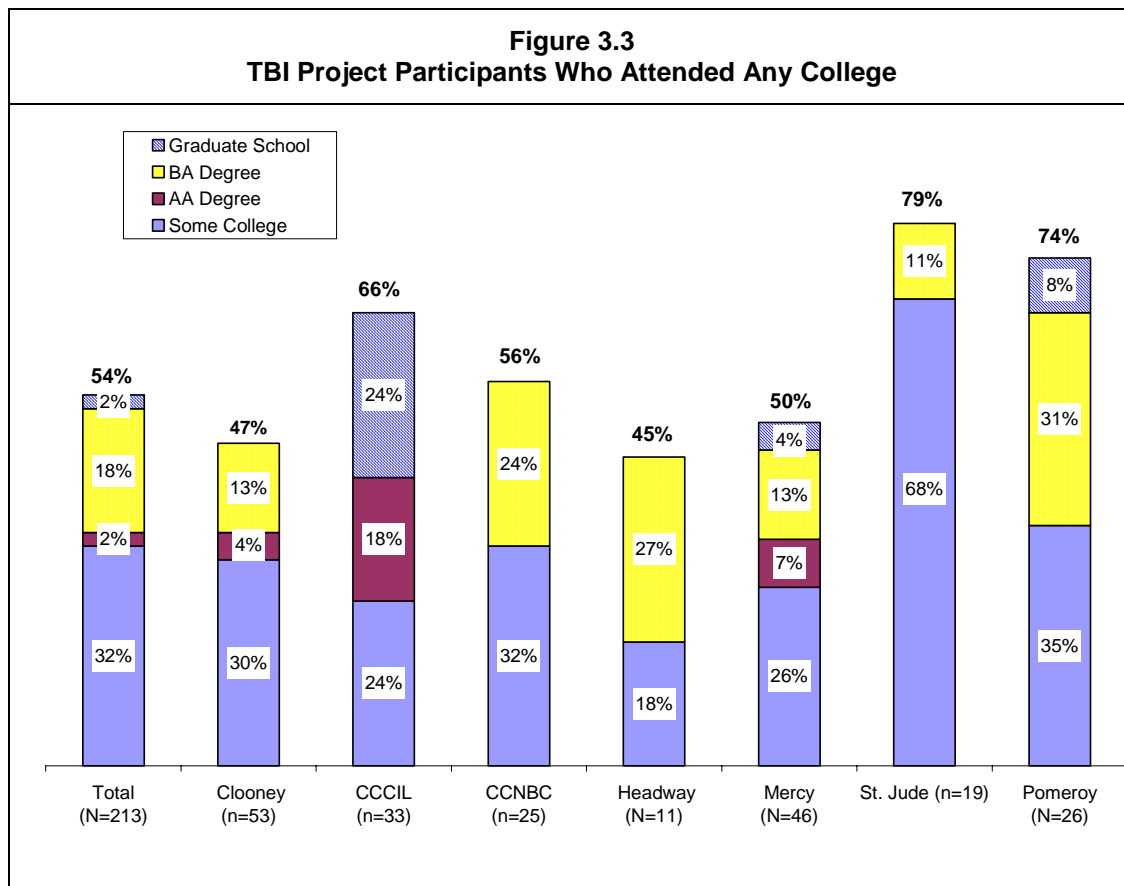
¹ U.S. Census Bureau, *California QuickFacts*, <http://quickfacts.census.gov>



Nearly all of CCNBC participants were white (92%). Pomeroy, which serves San Francisco County, had the most diverse participants in terms of ethnicity; 33% were non-white, including participants who were Hispanic, African-American and “other” ethnicities. Clooney, which serves Los Angeles County, served the largest proportion of Hispanic participants (17%), while St. Jude (in Orange County) served the largest proportion of Asians (11%).

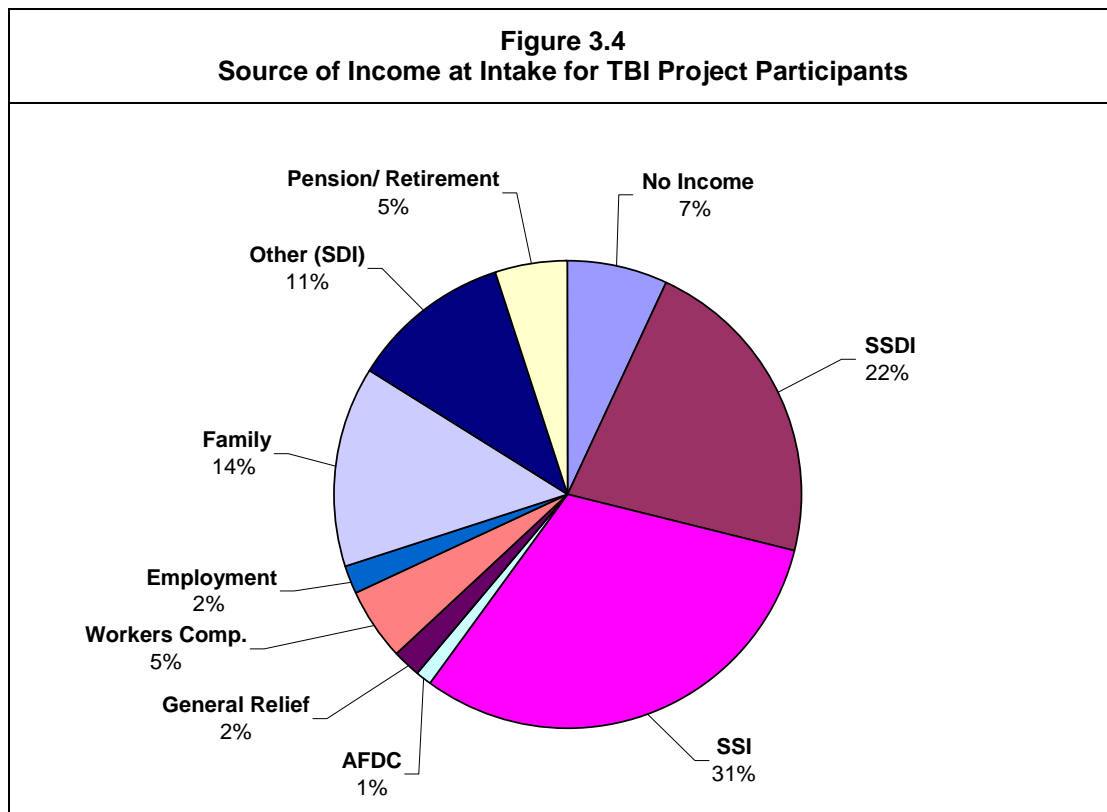
By and large, all but a few participants spoke English as their primary language (97%), another 2% spoke Spanish, while 1% spoke an Asian dialect. All of the participants at Making Headway and St. Jude spoke only English. Pomeroy had the largest proportion (8%) of participants who primarily spoke a language other than English.

Across all of the sites, only 11% of participants had less than a high school education, and one-third had obtained either a high school diploma or a GED as their highest level of education. Over half (54%) of participants had attended at least some college, though only 18% had earned a Bachelor’s degree. The proportion of participants who had attended at least some college varied widely across the TBI Project sites (see Figure 3.3). Approximately three-quarters of St. Jude (79%) and Pomeroy (74%) participants had attended college, while only 40% of Mercy’s participants had at least some college experience.



Almost two-thirds (62%) of the participants were single; another 18% were married, while 17% were divorced. Making Headway had the greatest number of single participants (91%), while Mercy had the fewest (48%). Clooney had the greatest number of married participants (28%), while CCCIL had the fewest (3%). CCCIL had the greatest number of divorced participants (30%).

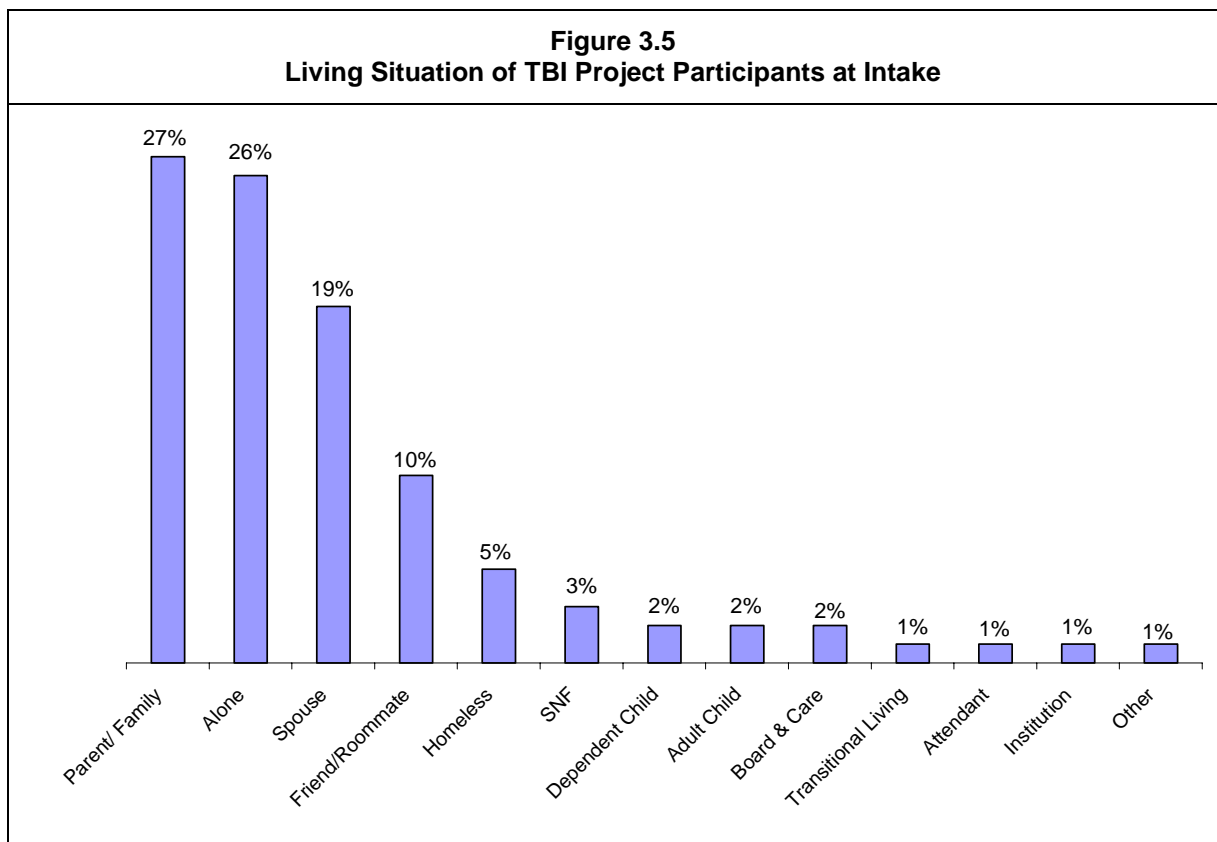
As Figure 3.4 illustrates, over half of all participants depended on some form of Social Security insurance as their primary income source. Almost a quarter (22%) of the participants were SSDI beneficiaries, and nearly one-third (31%) relied on SSI as their primary source of income. Participants were also supported by their families (14%) and received State Disability Insurance (11%). Seven percent of participants had no source of income.



CCCIL had the greatest proportion of participants without a source of income (22%) and also the largest proportion of participants receiving SSDI payments (28%) as their primary source of income. CCNBC had the largest percentage of participants relying on SSI payments (38%). Two-thirds of Pomeroy participants relied on either SSDI (19%) or SSI (46%) for income, the highest proportion across the sites. Pomeroy staff noted that social workers at the San Francisco General Hospital Trauma Center ensure that all patients who would be eligible for Social Security benefits have applied before they are discharged.

Clooney had the highest percentage of participants who depended on their families for financial support (23%), while nearly a third of Making Headway participants looked to some “other” source for their income (30%). Only 5% of participants overall received a pension or other retirement income, however, all but two of these individuals attended Mercy’s program.

Half of all participants lived with a family member, either a parent or other family member (27%), spouse (19%), dependent child (2%), or adult child (2%) (see Figure 3.5). On the other hand, over a quarter of the participants lived alone (26%), and 5% were homeless at the time they enrolled in the TBI Project. Only a few participants lived in a formal group setting, including transitional living programs (1%), board and care homes (2%), skilled nursing facilities (3%), or institutions such as a developmental center or state hospital (1%).



Pomeroy had the greatest proportion of participants living alone (42%), while St. Jude and Mercy had similar proportions of participants living with a parent or other family member. About one-third (30%) of Mercy's participants lived with a spouse, and one-fifth of St. Jude participants lived with either a friend or a roommate (21%). CCCIL had the greatest proportion of homeless participants (21%), while none of the individuals served by Mercy or CCNBC were homeless at program intake.

Source of income and living situation were two of the data items for which staff from at least one site noted that the study sample does not accurately represent the larger group of all TBI Project participants. Staff from St. Jude reported that they serve more participants who are homeless and without income than the figures for the study sample would indicate.

The evaluation also looked at a few data items that were available only on the TBI Project intake form, completed before an individual becomes a participant. Information for these data items is not as complete as for the assessment form, therefore we will mention these only briefly:

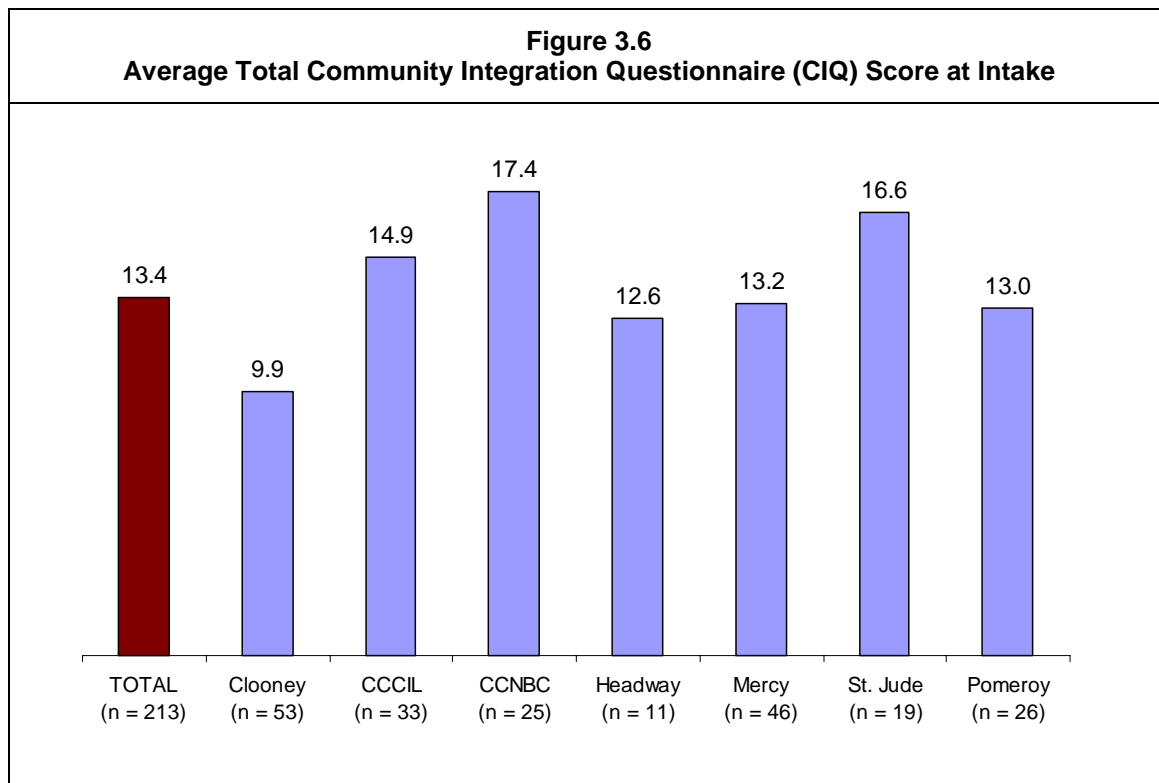
- Data on transportation was available for 156 individuals. Nearly all had some source of transportation (92%). Overall, about 27% of participants could drive themselves, 39% depended on family and friends for rides, and 36% used public transit. Making Headway participants were substantially more likely to have transportation problems, since only half of those for whom we had data used any of these means of travel.
- Information on monthly income was available for 72 participants. The average for these individuals was \$659.
- Information about history of mental illness was completed for 84 participants. Of these, 23% had previously diagnosed psychiatric disabilities.
- Data on history of seizures was available for 103 participants. About one-quarter (24%) of these individuals were identified as having seizures.

Community Integration

The evaluation used the Community Integration Questionnaire (CIQ) as the primary measure of participants' reintegration into their local communities. Developed for the TBI Model Systems program funded by the National Institute on Disability and Rehabilitation Research (NIDRR), the Community Integration Questionnaire (CIQ)² measures community integration among survivors of traumatic brain injury. The CIQ consists of 15 items organized into three subscales: home integration, social integration, and productivity. The questionnaire is scored to provide subtotals for each subscale, as well as for community integration overall. Scores are not assigned specific values, but represent a level of integration relative to the maximum possible score for each subscale and for the total instrument (29). A high score indicates greater integration, and a low score reflects less integration.

TBI Project staff administered the CIQ during each assessment. Figure 3.6 presents the average Total CIQ score by site at intake. Across all sites, participants averaged Total CIQ scores of 13.4 out of a possible 29 points. CCNBC and St. Jude participants had the highest average scores (just over 17), compared to Clooney's average Total CIQ score of 10 points.

² Barry Willer, Ph.D., <http://www.tbims.org/combi/ciq/>. See Chapter 5 for more detail on the CIQ.



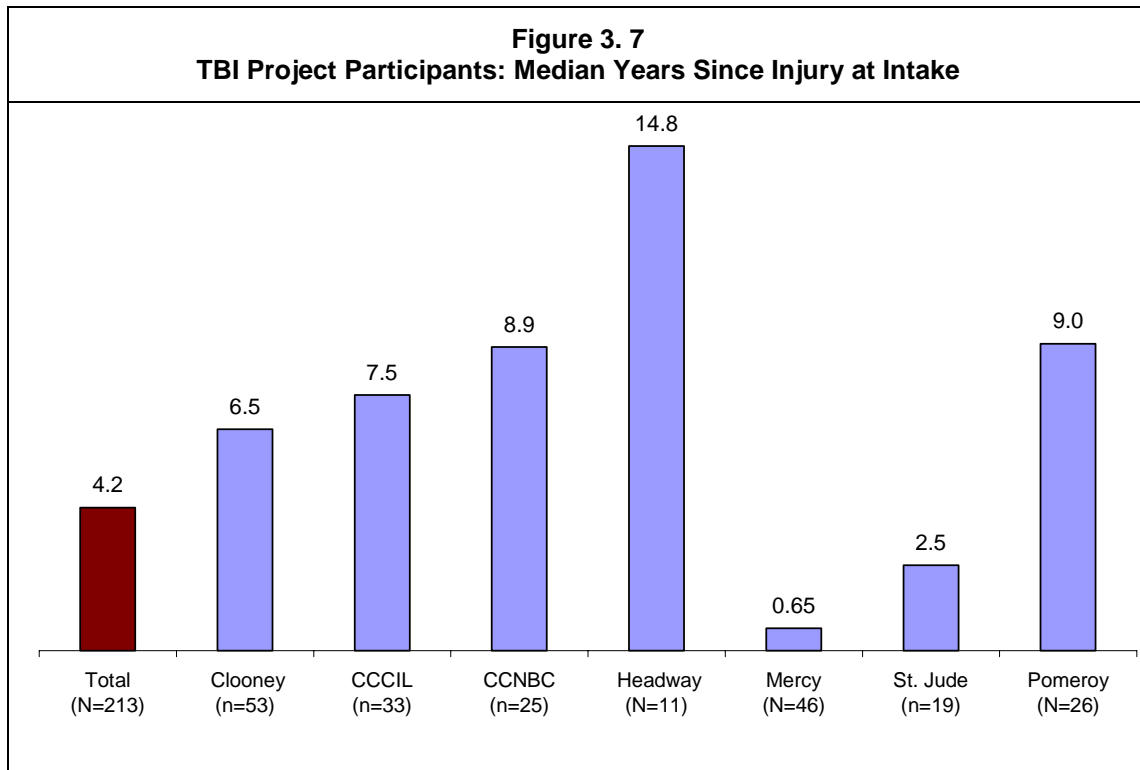
Characteristics Related to Participants' Injuries

On average, participants were 32 years old at the time of their injury, though age at injury ranged from one to 79 years of age. Mercy participants acquired their traumatic brain injuries slightly later than those served by other sites (average age of 35 years). St. Jude participants tended to acquire their traumatic brain injuries at an earlier age than the other site's participants, with an average age at injury of 28 years.

While information about participants experiencing multiple traumatic brain injuries was not a data item on the assessment form, site staff often noted multiple TBIs when recording the individual's date or age of injury. The evaluation team captured this information in the study database; however, the results under-represent the occurrence of multiple TBIs because the sites varied in how consistently they recorded the existence of multiple brain injuries. Across the sites, a total of 11 individuals with multiple TBIs were reported. This data item should be considered for inclusions in the project's future data collection efforts.

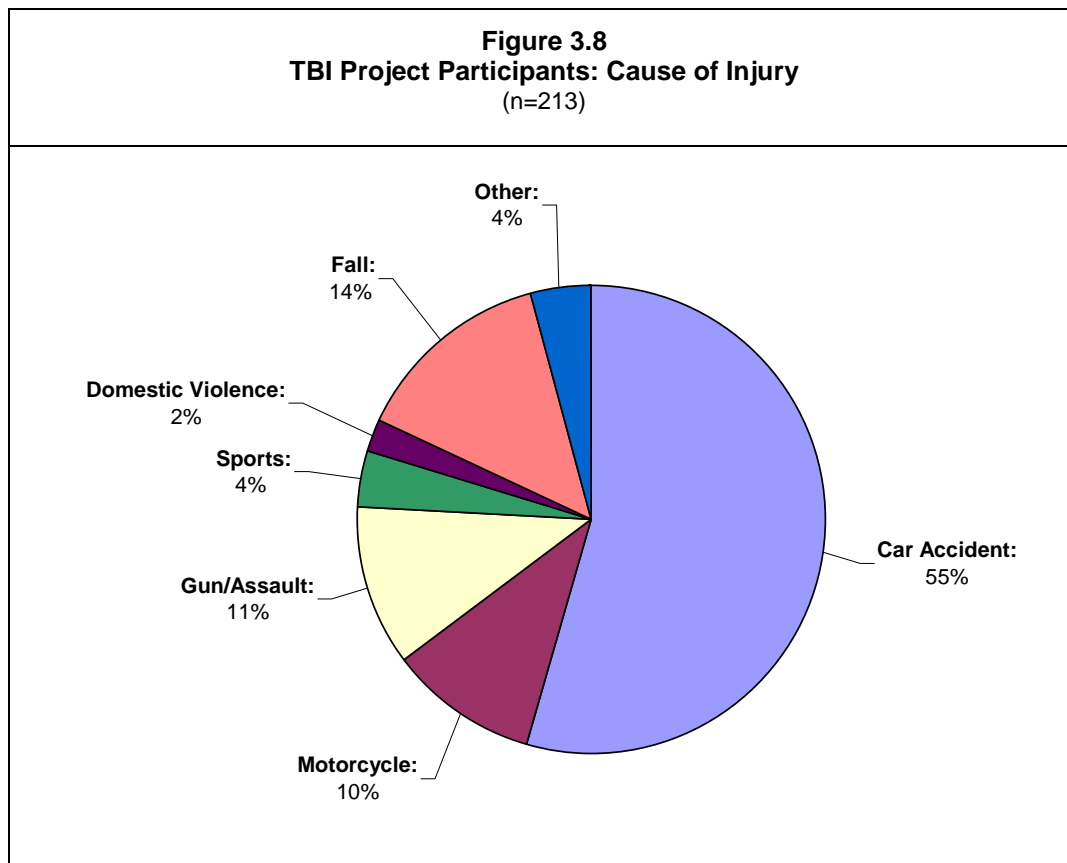
The length of time between a participant acquiring a traumatic brain injury and enrolling in the program averaged ten years. Nonetheless, over one-quarter (26%) of participants had experienced their TBI in the previous year, and the median (middle of the range) time between injury and

intake was 4.2 years. Because a few participants enrolling in the project many years after injury can distort the average, we present the median values for this measure in Figure 3.7. Reflective of its location in an outpatient rehabilitation unit and its service model, participants enrolled in Mercy's TBI Project relatively sooner after injury (median of .65 years, or about 8 months) than did participants at other sites (see Figure 3.7). In contrast, the median length of time between injury and intake for Pomeroy participants was nine years, and 15 years for Making Headway participants.



As Figure 3.8 illustrates, the most frequent cause of participants' traumatic brain injuries was a car accident (54%). This is consistent with national data suggesting that half of traumatic brain injuries that require hospitalization are caused by motor vehicle accidents.³ St. Jude had the greatest proportion of participants acquiring their injury from a car accident (68%), while Clooney had the smallest (42%). The second most common cause of injury was a fall (14%). Smaller proportions of participants were injured during an assault or gun incident (11%) or in a motorcycle accident (10%). Pomeroy had the greatest proportion of participants acquiring their injury from an assault or gun incident (23%), while CCNBC had the greatest proportion of participants acquiring their injury from a motorcycle accident (16%).

³ Sosin, D.M., Sniezek, J.E., & Thurman, D.J. (1996) "Incidence of Mild and Moderate Brain Injury in the United States," *Brain Injury*, 10(1): 47-54, 1991.



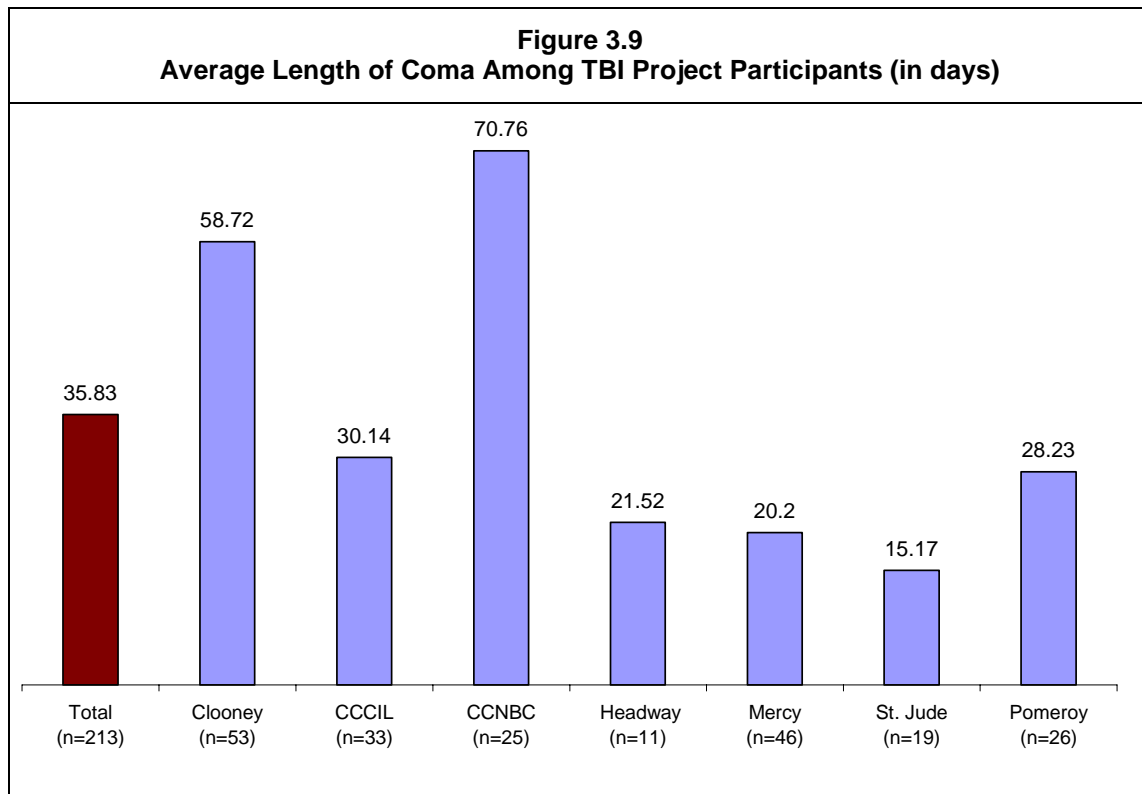
Since a portion of the funding that supports the TBI Project comes from fines for violating California's seatbelt law, interest in whether participants injured in a car or motorcycle accident were wearing safety equipment is high. Unfortunately, information about use of seatbelts or helmets was available for only about half of participants who were involved in a car or motorcycle accident.⁴ Of the 85 individuals for whom this information is available, almost three-quarters (71%) were wearing safety equipment (i.e., seat belt or helmet) when they acquired their TBI. Within this subsample of participants, 72% of those injured in a car accident were wearing a seatbelt at the time, while 64% of those injured in a motorcycle accident were wearing a helmet.

Almost half of all participants experienced a coma after their traumatic brain injury (49%), while nearly a third did not (31%). Quite a few participants (18%) could not say whether or not their injuries resulted in a coma. The proportion of participants for whom information was unknown varied across the sites for this and other data items related to participants' injuries. The four sites that have been in operation for the longest period of time generally had more complete data about participants' injuries than did sites funded more recently. As established programs, they have had

⁴ Like several data items mentioned earlier (history of mental illness or seizure disorder, availability of transportation, income at intake), this information was collected via the intake form, completed before an individual becomes a participant.

time to develop relationships with local hospitals that can facilitate access to their participants' medical records. Because they are hospital-affiliated, Mercy and St. Jude, in particular, had better access to hospital data about injuries, and thus had very low rates of missing data for these data items. CCCIL on the other hand, uses a service model based on the independent living philosophy, and the site's staff is more likely to rely on participant reports about their injuries than to seek medical documentation.

Participants' comas ranged in duration from about an hour to ten months, with an average of just over one month of unconsciousness. About half of the participants had comas of two weeks or less. On average, CCNBC participants had the longest comas, 71 days, compared to participants served by other sites. CCNBC also had the largest percentage (54%) of participants for whom information about coma was missing.



Over a third of all participants experienced amnesia after their traumatic brain injuries (36%), while a quarter did not (24%). Information about amnesia was missing for 39% of participants overall. Mercy had the largest proportion (72%) of participants who had amnesia after their injury. On the other hand, only 10% of Making Headway participants were identified as experiencing amnesia. It is interesting to note, however, that 82% of Headway's participants reported they could not remember if they had had amnesia associated with their injury. On average, participants with amnesia experienced the condition for 80 days (or about two and a half months). Clooney participants averaged the longest period with amnesia, 252 days (or about eight months), though half had periods of amnesia of three months or less.

Over three-quarters of all participants were hospitalized after their traumatic brain injuries (76%), while only 8% were not. Seventeen percent of participants could not say whether or not they had been hospitalized after their injury. The duration of hospitalization varied widely across participants. While the average hospital stay was about three and a half months (103.66 days), half were in the hospital for less than two months (49 days) and 12% were hospitalized for less than a week. CCNBC had the smallest proportion of participants hospitalized (38%), while Mercy had the largest (96%). Clooney participants averaged the longest hospital stays, nearly six months (180 days).

Substance Abuse

A large body of evidence exists to document the relationship between intoxication and TBI. Because of this awareness, the TBI Project included data items about substance abuse in the common assessment form. This section first presents a short summary of some of the research findings on the link between TBI and substance abuse, then discusses alcohol and/or drug use among the evaluation's study sample.

Research data suggest that as many as:

- 20% to 30% of persons with traumatic brain injury (TBI) are intoxicated at time of injury.
- 50% to 60% of adolescents and adults in acute rehabilitation have prior histories of substance abuse.

A recent study in a large, publicly funded, community-based substance abuse treatment program found that three-quarters (74%) of clients screened had experienced at least one TBI with loss of consciousness, and 33% of clients had experienced at least one TBI with one hour or longer loss of consciousness.⁵

Several studies have shown that people who sustain a TBI are twice as likely (35%) as others in the community (17%) to have been a significant user or abuser of drugs or alcohol—or both—before their injury. Furthermore, use of drugs and/or alcohol often causes accidents that lead to TBI, for example, while driving under the influence of alcohol. Among TBI patients receiving acute medical rehabilitation, as many as two-thirds have evidence of prior substance use

⁵ Brain Injury Association of Ohio, *Substance Abuse and Traumatic Brain Injury Training*, July 2003.

disorders (Corrigan, 1995).⁶ Although most individuals with TBI reduce their alcohol or other drug consumption right after injury, many people tend to return to pre-injury levels of use by two years post-injury.⁷

Clinicians and researchers have repeatedly observed that cognitive and emotional impairments caused by brain injury present unique problems when addressing co-existing substance use problems. Use/abuse of substances can bring major additional challenges for an individual with TBI—at a time when he or she doesn't need to carry an even heavier load. Use of alcohol/drugs after TBI is known to result in:

- Slower recovery from the brain injury;
- Further damage to an already injured brain;
- Increased frequency of aggressive and/or anti-social behaviors;
- Interference with thinking processes already diminished due to injury; and
- More failure in work, school, and parenting roles.⁸

The project sites collected two types of information relevant to the issue of substance use. First, at each initial assessment staff asked participants for information about whether alcohol or other drug use interfered with daily activities, whether they had a history of substance abuse and if so, how long they had been drug-free, and whether they were currently receiving any help dealing with an alcohol or drug problem. Second, during the questions about participants' injuries, they asked whether the injuries were related to the use of drugs or alcohol. As shown in Figure 3.10, the proportion of participants with a prior history of substance abuse varied from a low of 18% at

Figure 3.10 History of Substance Abuse at Enrollment																
Measure	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
History of substance abuse																
Yes	70	34%	11	21%	11	35%	8	35%	6	55%	21	50%	3	18%	10	39%
No	134	66%	42	79%	21	66%	15	65%	5	46%	21	50%	14	82%	16	62%
How long substance free (years)																
Mean	4.95		3.5		8.89		5.53		1.42		1.05		0.83		10.39	
Median	1.33		2.5		6.0		2.0		1.0		0.16		0.83		14	

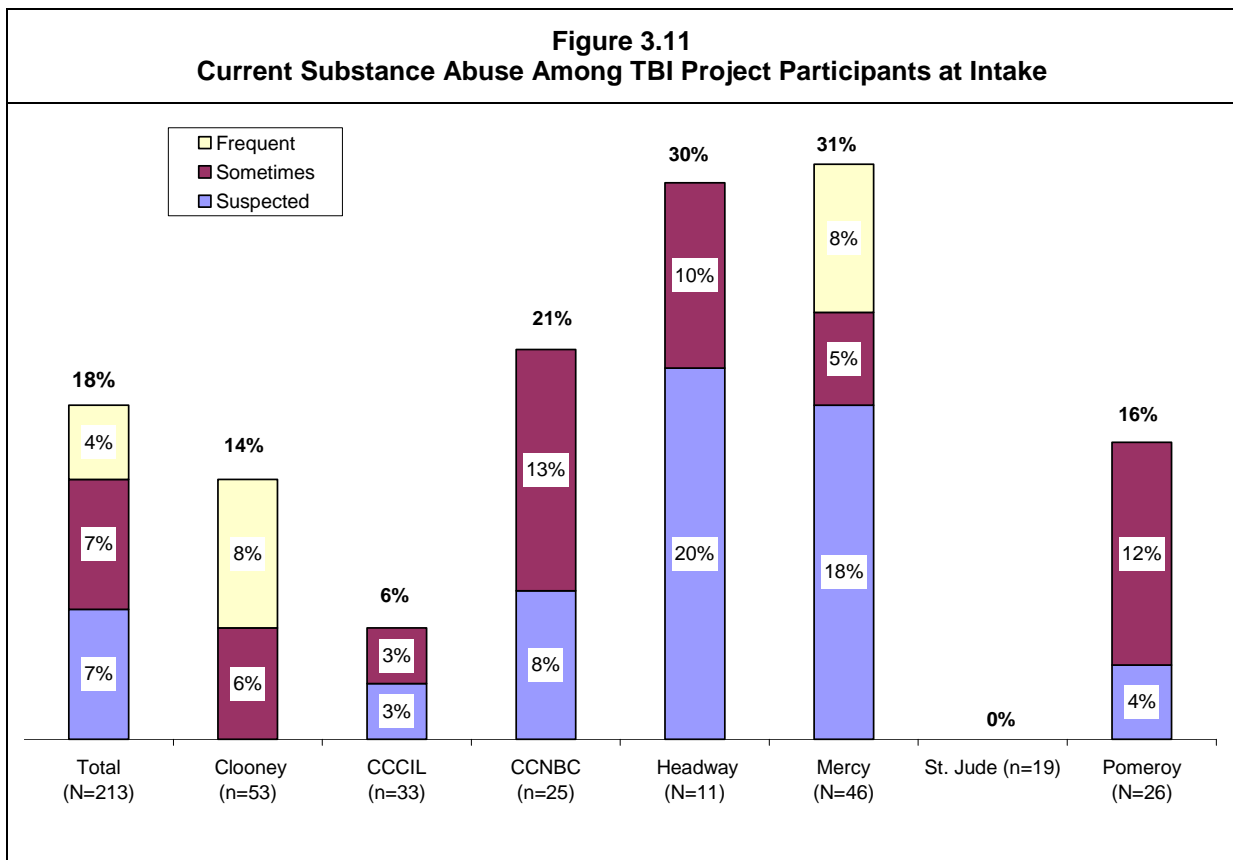
⁶ Corrigan, J. D. (1995). *Substance abuse as a mediating factor in outcome from traumatic brain injury*. Archives of Physical Medicine and Rehabilitation, 76 (4), 302-309.

⁷ Kreutzer, J. S., Witol, A. D., & Marwitz, J. H. (1996). *Alcohol and drug use among young persons with traumatic brain injury*. Journal of Learning Disabilities, 29 (6), 643-651.

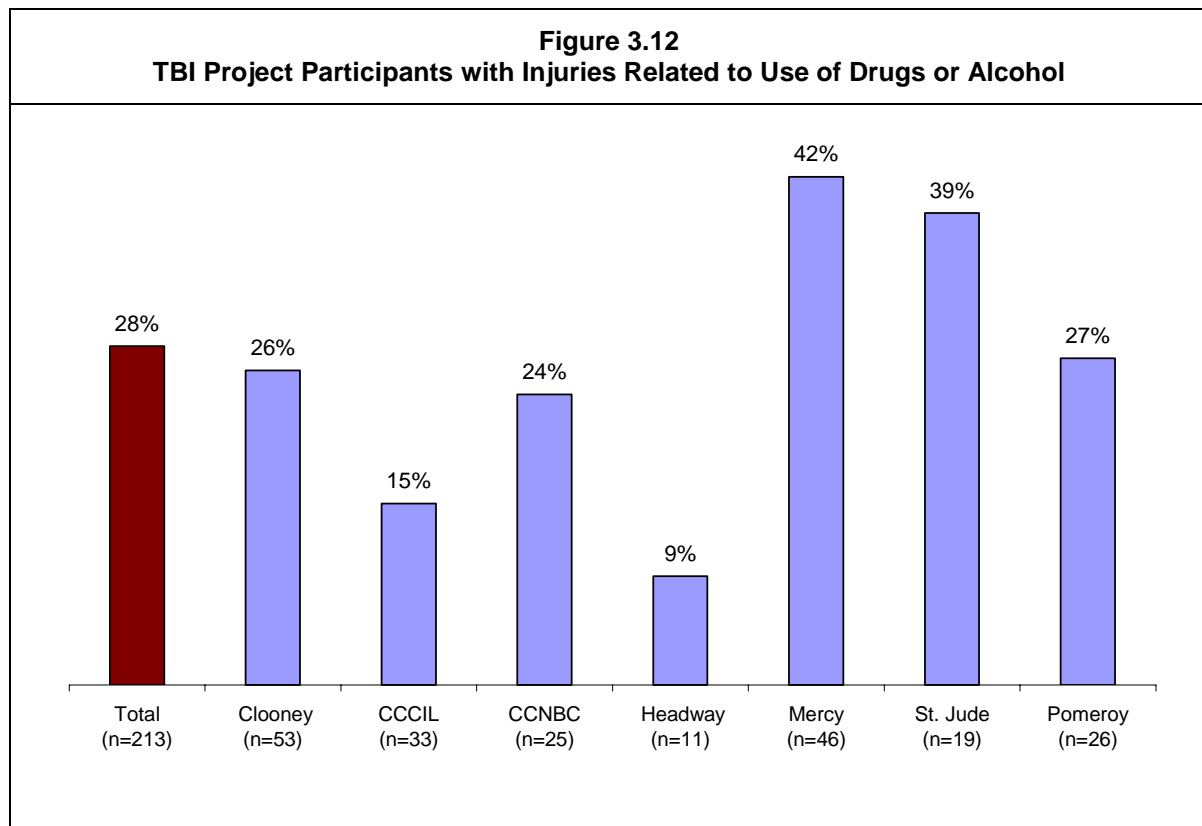
⁸ Mount Sinai School of Medicine, *TBI Consumer Report #6: Coping with substance abuse after TBI*, Research and Training Center on Community Integration of Individuals with Traumatic Brain Injury, no date.

St. Jude to a high of 55% at Making Headway. Overall, sites reported that just over one-third of program participants (34%) had a history of substance abuse prior to entering the program. This is consistent with the national estimate of 35% mentioned earlier. When asked how long they had been alcohol- or drug-free, these participants reported being alcohol- or drug-free for an average of five years at enrollment, ranging from a high of 14 years on average at Pomeroy to a low of less than one year at St. Jude.

Overall, 18% of TBI Project participants were identified as—or suspected of—having a problem with drug or alcohol abuse at the time they enrolled in the program (see Figure 3.11). It is interesting to note that none of St. Jude’s participants were identified as having a substance-abuse problem at the time of their initial assessment. Whether this reflects a systematic difference in the types of individuals being served there, or simply reflects the fact that the sites have not received systematic training on how to identify substance abuse problems is unclear. In contrast, almost one-third (31%) of Mercy’s participants had a confirmed or suspected substance abuse problem at the time they entered the program.



Sites reported that as a group, 28% of participants' traumatic brain injuries were related to use of drugs or alcohol, either by the TBI survivor or another individual. This figure is consistent with research that showed between 20% to 30% of persons with TBI are intoxicated at time of injury.⁹ An additional 11% of participants could not say whether or not use of alcohol or drugs was a factor in receiving their injury. As Figure 3.12 shows, the sites varied widely in the proportion of their participants whose injuries were related to use of alcohol or drugs. Mercy's participants represented the upper end of the range, with 42% of participants' injuries related to substance abuse, while alcohol or drugs were involved in the injuries of only 9% of Headway participants.



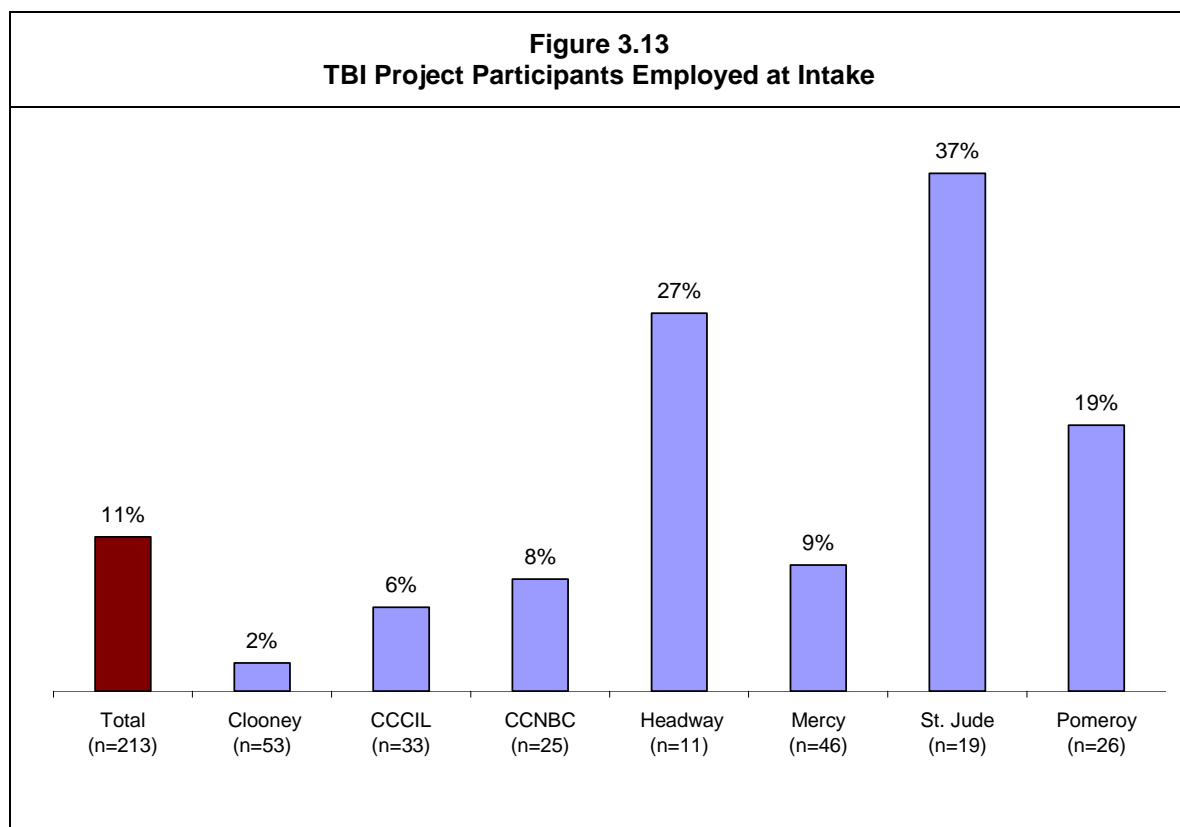
Vocational Status at Intake

As Figure 3.13 illustrates, 24 participants were working when they enrolled in the TBI Project (11% of the study sample). This number includes a few individuals who were employed but on disability leave at the time they entered the program. St. Jude had the largest proportion (37%) of participants employed at intake, while only 2% of Clooney's participants were working. The workers were fairly evenly divided between those working full-time and those working part-time.

⁹ Brain Injury Association of Ohio, *Substance Abuse and Traumatic Brain Injury Training*, July 2003.

In addition, a few participants were working in supported employment positions at intake. All four with jobs in supported employment worked part-time. Three were CCNBC participants, and one was enrolled in Pomeroy's program.

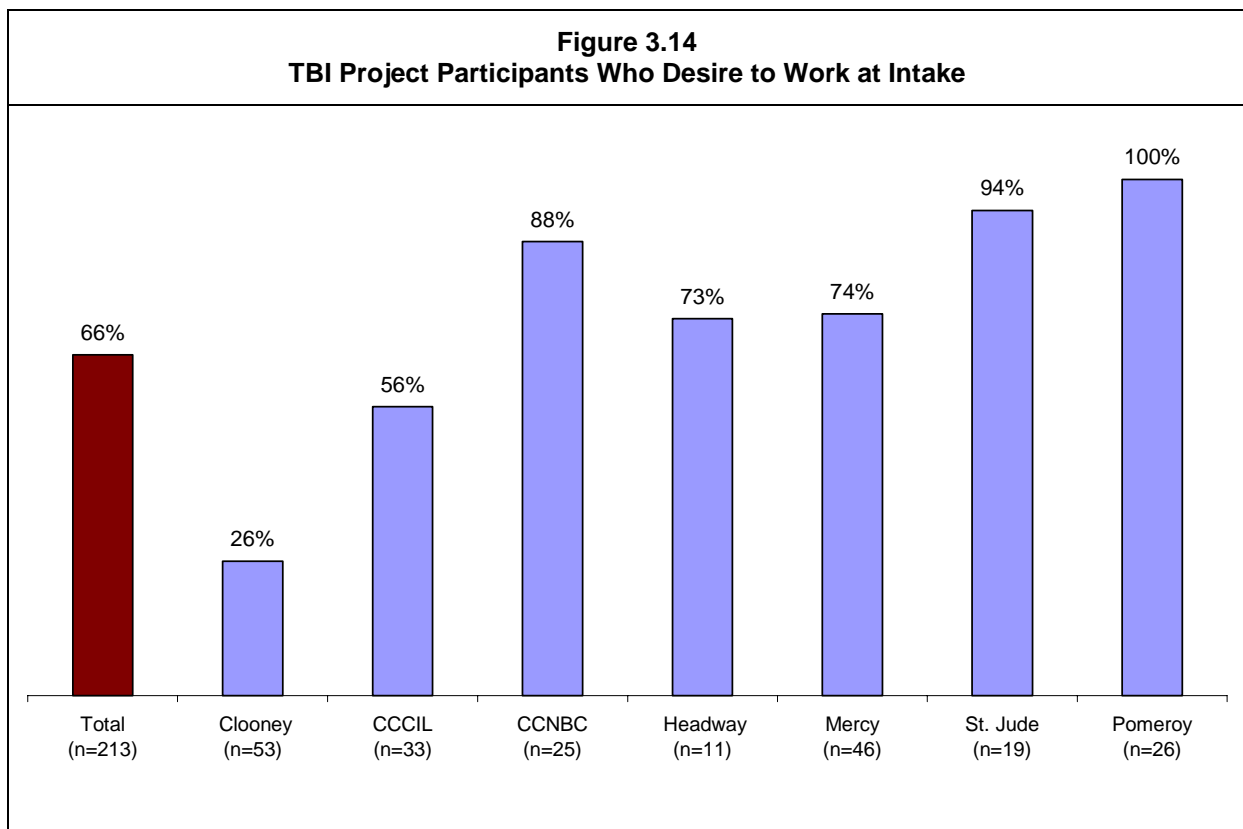
Almost one-quarter (22%) of participants were clients of the Department of Rehabilitation (DR) at the time they joined the Project. CCNBC had the largest proportion (48%) of participants who were DR clients at intake, compared to 7% of Mercy participants, and 10% of Headway's participants. In addition, another 9% of participants from all of the sites except Clooney and Headway were enrolled in another vocational program when they entered the TBI Project. Half of those in a vocational program were receiving prevocational services, and one-third (36%) were in a skills training program.



The assessment form included questions asking whether the participant was employable, and whether the individual had expressed a desire to work or a desire not to work. The sites used various means of determining that a participant was employable. For example, CCCIL staff considered several factors, including whether the participant had held a job during the past year, whether the individual was interested in employment, and if he or she was free of disability-related problems that would interfere with work. Mercy staff, on the other hand, considered a participant employable if his/her physician had released the individual to return to work. Making Headway used no set criteria, while Clooney staff considered the participant's desire to work to be the best indicator of employability.

Across all of the sites, staff considered 23% of participants to be employable at intake. CCNBC assessed 74% of applicants to be employable, while less than 10% of Clooney and Mercy participants were considered employable.

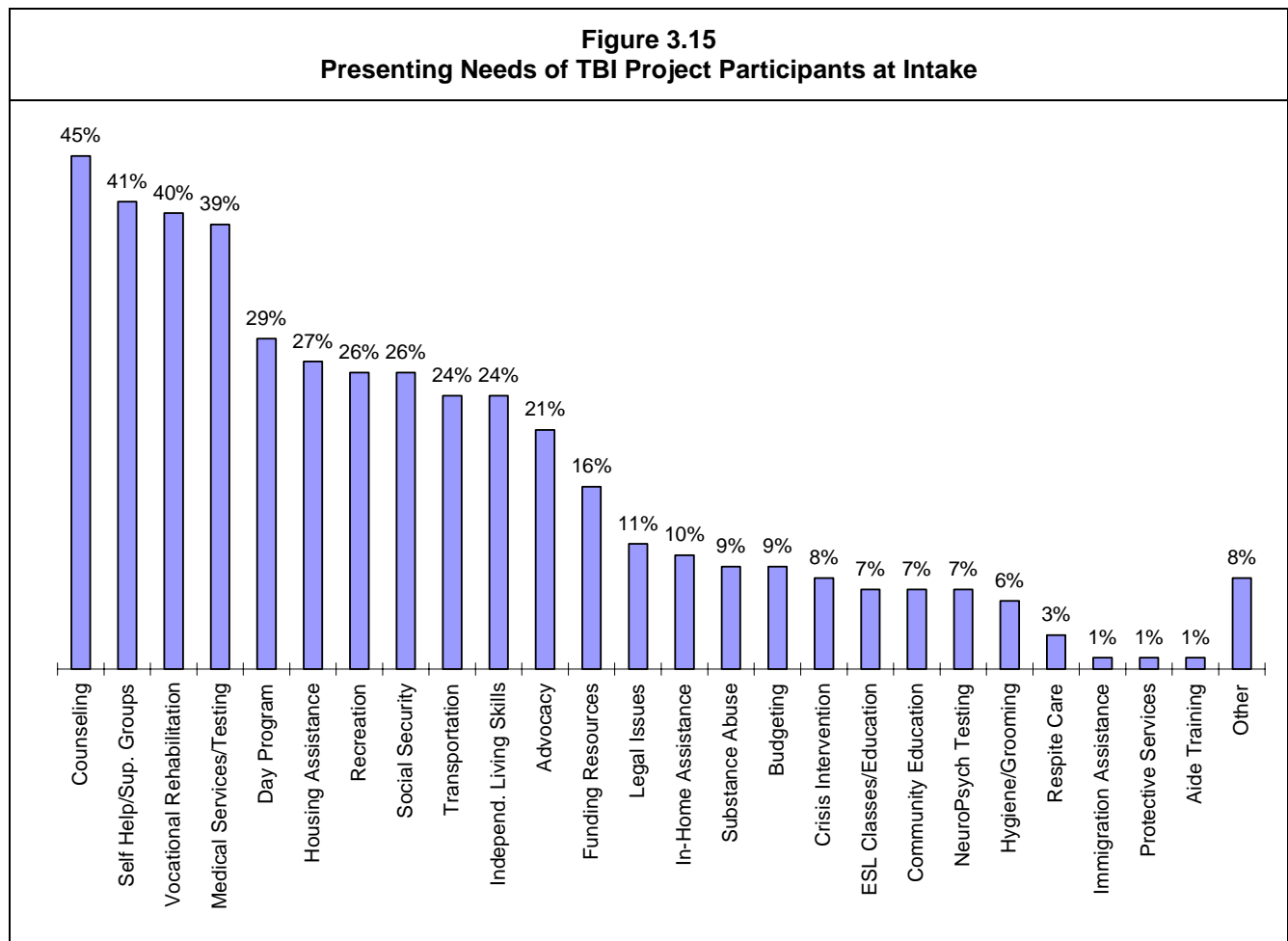
Regardless of whether TBI Project staff considered individuals to be employable, a full two-thirds of participants expressed a desire to work at the time they enrolled in the program (see Figure 3.14). A majority of participants at all sites except for Clooney wanted to return to work, including all of the Pomeroy participants, 94% of St. Jude participants, and 88% of CCNBC participants.



At the same time, 29% of participants stated their desire not to work at the time they entered the Project. Over half (53%) of Clooney participants did not want to be employed, but the most interesting numbers were the proportions of participants at CCCIL and Pomeroy who stated they did not want to work. While 56% of CCCIL participants wanted employment, 66% did not want to work. Similarly, even though all of Pomeroy's participants wanted to work, 12% did not want to be employed. These findings may appear to be paradoxical, however, they clearly illustrate the ambivalence that participants may hold about returning to work. The draw of returning to a "normal" life as an employee is often offset by concerns about being able to perform work tasks with TBI-related impairments, or about maintaining the financial stability of Social Security and Medicaid/Medicare benefits when a job may not work out.

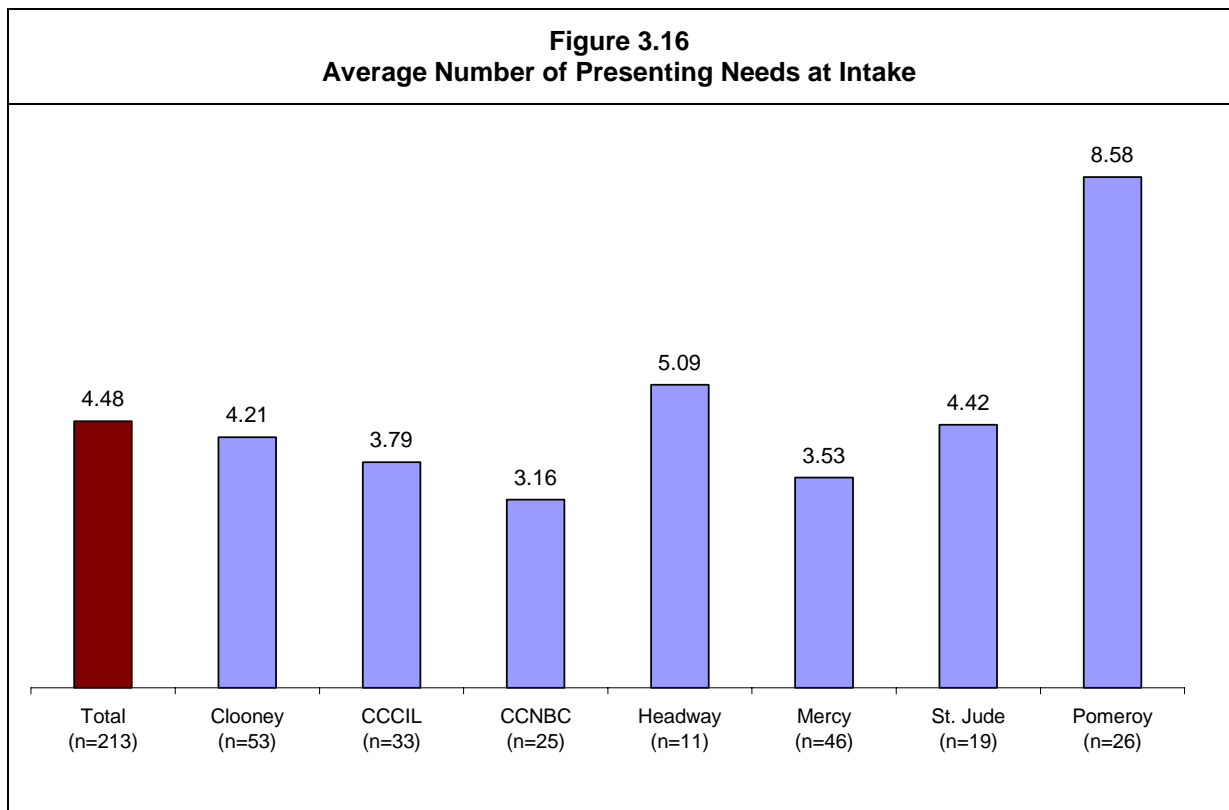
Service Needs at Intake

The TBI Project assessment form includes a checklist of 26 types of services that a participant might need. Figure 3.15 shows the proportion of participants across all sites that needed each service included in the checklist at the time they enrolled in the program. Across all sites, participants most frequently needed counseling (45%), self-help/support groups (41%), and vocational rehabilitation (40%). As we discuss below, the frequency with which specific service needs were reported for participants varied across sites.



Interviews with project staff revealed that each site approaches the needs assessment process slightly differently, and that each staff member may use a different approach to identifying participant needs. For example, staff at several sites ask participants what types of services they think they need, and their responses are noted on the checklist. In contrast, Pomeroy staff explain each service to the participant each time an assessment is done, so that the participant—as well as

the staff member—can decide if the service is appropriate. As a result, as Figure 3.16 indicates, substantially more presenting needs were identified for Pomeroy participants, 8.6 on average, than for participants at other sites (average of 4.5 needs across all sites). At the other end of the range, CCNBC staff identified an average of 3.2 service needs per participant upon enrollment, and Mercy participants needed an average of 3.5 services at intake.



Other factors may influence the identification of participant needs. Site staff indicated that the needs assessment process does not occur in a vacuum—that the resources available in the local community and the specific services that the site’s host organization provides may also influence whether or not staff members identify a need for a specific service. Figure 3.17, which shows the top three service needs identified for participants in each site, offers examples of how these factors may shape the needs assessment process. The Mercy site is co-located with an outpatient rehabilitation facility, which provides assessments and testing as well as physical, occupational, and speech therapies. Not coincidentally, medical services and testing are the type of service most frequently (70%) identified as participant needs at this site. Similarly, staff at Clooney, which operates a day program, indicated a large proportion (53%) of participants as needing day program services. Of course, it is also likely that some individuals may choose to come to specific programs because they need the services the program offers.

Figure 3.17 TBI Project Participants: Top Three Service Needs by Site					
Project Sites	Rank				
	1		2		3
	Service	%	Service	%	Service %
Total (n=213)	Counseling	45%	Support Groups	41%	Vocational Rehabilitation 40%
Clooney (n=53)	Counseling	57%	Day Program	53%	Support Groups 43%
CCCIL (n=33)	Housing Assistance	58%	Counseling	39%	Support Groups 39%
CCNBC (n=25)	Vocational Rehabilitation	72%	Independent Living Skills	44%	Transportation 32%
Headway (n=11)	Advocacy	82%	Support Groups	64%	Counseling 55%
Mercy (n=46)	Medical Services	70%	Counseling	54%	Support Groups 46%
St. Jude (n=19)	Advocacy	79%	Vocational Rehabilitation	68%	Social Security 53%
Pomeroy (n=26)	Vocational Rehabilitation	81%	Support Groups	69%	Funding Resources 58%

In the following chapter we examine the services that the TBI Project sites provide to address the needs identified among participants at intake.

4. Participant Services Provided by the TBI Project

As described in Chapter 1, California's Welfare and Institutions Code Section 4353-4359 mandates that the TBI Project provide a specific set of services to its participants, including service coordination, community reintegration, supported living, and vocational support. The project's data collection system focuses primarily on documenting the provision of these core participant services, although it also documents the provision of several other services related to its funding through the interagency cooperative agreement with the Department of Rehabilitation (DR).

The evaluation used two sources of information about service provision among the TBI Project sites. First, we used data from the project's quarterly reporting system, which collects aggregate data about the number of participants served, units of service provided by type of service, number of inquiries, and community services provided. Second, we used information collected on the project's six- and 12-month assessment forms about the services used by the 213 individuals in our study sample.

This chapter first examines services provided to all participants served during Fiscal Year 2003-2004 (FY03-04), as well as the amount of time that site staff devote to providing each type of service. We then describe the services used by participants in the evaluation study sample.

Services Provided to All Fiscal Year 2003-2004 Participants

The participant service process invariably starts with someone contacting a project site—either the TBI survivor, a family member or caregiver, or another service provider. This section describes the service process for an applicant from that first phone call, through assessment, service planning, provision of core services, and follow-up. We also discuss the number of participants to whom the TBI Project sites provided these services during FY03-04, and the amount of time that staff spend in each of these types of activities.

Intake

The Department of Mental Health (DMH) has asked the sites to collect information about all potential participants during their first contact with the project. This practice is called the “intake,” regardless of whether or not the relevant TBI survivor becomes an active participant of the project. The intake process involves gathering information about the caller's personal characteristics and major needs or problems, so that staff can determine if the TBI survivor is eligible for project services, or can be referred to another agency as needed. All of the sites except for CCCIL use a common intake form to collect this information (see Appendix B).¹ CCCIL uses its host organization's intake form, which contains basic participant information, but

¹ CCNBC staff designed a site-specific intake form that combines all of the items from the TBI Project intake and elements from the host organization's intake form to collect more specific information about applicant levels of functioning.

Information Collected at Intake

Contact information

Applicant:

- Relation to Caller
- Age
- Gender
- Ethnicity
- Primary Language
- Marital Status
- Living Arrangement
- Date of Injury
- Age of Onset
- Income
- Diagnosis
- Type of Accident
- Safety Equipment Worn
- Alcohol Involved

does not include information about whether the individual had an existing mental illness or seizure disorder, transportation, or whether the TBI survivor was wearing a seatbelt or helmet at time of injury.

Because collection of intake information is not limited to TBI survivors who are enrolled in project services, site staff generally complete more intakes than they do assessments or service plans. On average, the sites conducted only about half as many initial assessments as intakes in FY03-04 (see Figure 4.1). The variations in this ratio are a result of differences across sites in their procedures for conducting intakes. Staff at the four original sites (Clooney, CCCIL, Mercy, and St. Jude) are likely to complete an intake form for anyone with a brain injury who calls the site, while staff at the new programs tend to collect intake data only on those TBI survivors most likely to enroll in services.²

Another difference in procedures for conducting intakes is reflected in the variation in the amount of time spent completing the intake process. As a group, project staff spend an average of about an hour conducting each intake. CCNBC staff, however, spent an average of half an hour on the intake process, while Headway staff spent just over an hour. Pomeroy reported an unusually long intake process averaging almost two hours, conducted only with participants who enrolled in the project. During the intake, both service coordinators and the site project director interviewed the participant. Staff at this site also considered any service planning conducted at these meetings to be part of the intake process.

Figure 4.1
Intakes and Assessments Conducted in Fiscal Year 2003-2004, By Site

Measure	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Number of Intakes	363	123	22	22	34	55	75	32
Average Hours per Intake	0.9	0.9	0.9	0.6	1.2	0.9	0.6	1.9
Number of Initial Assessments	202	34	18	27	27	44	17	35
Average Hours per Initial Assessment	1.2	1.1	0.5	0.6	1.6	1.4	1.5	1.3
Ratio of Initial Assessments to Intakes	0.6	0.3	0.8	1.2	0.8	0.8	0.2	1.1

² Tables displaying more detailed information on TBI Project services by site are available in Appendix A-2: Supplemental Tables on Fiscal Year 2003-2004 Site Statistics.

Initial Assessment

The assessment collects in-depth information about a participant in order to determine the participant's need and/or eligibility for services, the appropriate mix of services, and level of care or support needed. Project staff conduct assessments at intake and at regular six-month intervals after intake. Completion of the first assessment is an important milestone within the TBI Project, since the date of that assessment is the date on which a new participant file is opened for the individual.

For the most part, the sites use a common data collection form to conduct assessments, included in Appendix B of this report. Several sites, including Clooney and CCCIL, supplement the information collected via this form with an additional vocational assessment. Pomeroy staff take into consideration factors not included on the common assessment form, including the participant's functional limitations and ability to organize his/her thoughts. Mercy participants meet with both the site's service coordinator and neuropsychologist to complete the initial assessment. CCNBC supplements the TBI Project assessment form with more detailed site-specific intake and assessment forms. The site's staff developed the additional data tools so that their data collection would be consistent with the forms used by the host organization, and in anticipation of applying for certification from the Commission on Accreditation of Rehabilitation Facilities (CARF).

The sites also vary in how they approach completion of the assessment process. For example, Pomeroy conducts the assessment during two meetings—the first to fill out the various enrollment forms, and the second to complete the actual assessment. CCCIL, on the other hand, does both the intake and assessment at the same meeting. Several sites noted that the initial assessment process might include assisting participants to secure medical documentation of their TBI.

Follow-Up Assessments

The TBI Project sites are required to repeat participant assessments at regular intervals of six months up until 18 months after enrollment in the program (and annually thereafter). Site staff use the common assessment form to conduct these evaluations, which may be completed in person or over the phone. During Mercy's follow-up assessments, everyone on the site's service team assesses the participant, including the physical therapist, occupational therapist, and speech therapist. Interestingly enough, this extended process did not seem to increase the average amount of time needed to complete the follow-up (see Figure 4.2).

At most of the sites, participants who continue to actively use TBI Project services for more than 18 months after joining the program are thereafter assessed annually on the anniversary of their enrollment (i.e., at 24 months, 36 months, etc.). Mercy is an exception to this rule; staff at this site consider a participant to have completed the program after they conduct the 18-month assessment. Any participants who return to the program for assistance after that point are treated as if they are new applicants. Thus, information on annual assessments is available from three of the four original sites, plus Pomeroy, since these were the only sites that had been in operation

Figure 4. 2 FY03-04 Follow-Up Assessments By Site								
6, 12, and 18-Month Assessments	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Number of 6 Month Assessments	106	12	14	5	7	33	16	19
Average Hours per 6 Month Assessment	0.8	2.0	0.5	0.5	0.8	0.5	0.8	0.6
Number of 12-Month Assessments	90	5	8	0	0	35	17	25
Average Hours / 12 Month Assessment	0.6	1.6	0.5	-	-	0.5	0.9	0.5
Number of 18 Month Assessments	71	1	1	0	0	43	11	15
Average Hours / 18 Month Assessment	0.6	1.0	.5	-	-	0.5	0.6	0.7
Number of Annual Assessments (active cases only)	98	7	18	0	0	0	46	27
Average Hours per Annual Assessment	0.7	1.6	0.5	-	-	-	0.7	0.5

long enough to have conducted annual assessments on any of their participants. These annual assessments also generally took longer to complete than the routine six-month follow-ups.

As Figure 4.2 illustrates, the number of six-, 12-, and 18-month follow-ups was fairly small, especially at the newest sites. As Chapter 5 discusses, the relatively small number of participants for whom follow-up data are available poses some challenges for assessing the effectiveness of the program and suggests a longer data collection period is needed to develop more conclusive findings.

Individual Service Plan

As one of the TBI Project staff said, the purpose of the participant's Individual Service Plan (ISP) is to "help define the direction of services and what to expect from the program." The Welfare and Institutions Code requires sites to develop and use an ISP to assist participants to move to increased levels of independence and employment. When an individual is determined eligible for services, site staff and the participant collaborate in developing the plan to document goals, tasks the participant will complete to progress toward those goals, and actions the TBI staff commit to taking in support of the participant's efforts. In addition to goals and tasks, the ISP includes target timeframes for meeting the goals.

Figure 4.3 summarizes the large variation in the numbers of initial ISPs written over the course of FY03-04. The high number of initial ISPs at Pomeroy reflects a different service planning procedure from the other sites, in which a new plan is written for each service goal task. This difference is also illustrated in the fact that Pomeroy reported more than six times as many new ISPs as they did initial assessments during the period.

Figure 4.3
FY03-04 Individual Service Plans By Site

Measure	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Number of Newly Written ISPs	369	35	21	5	28	30	17	233
Average Hours per New ISP	0.6	1.0	0.4	1.2	0.8	0.8	0.4	0.4
Ratio of New ISPs to Initial Assessments	1.0	0.3	1.0	0.2	0.8	0.6	0.2	7.3
Number of Updated ISPs	361	19	35	6	37	25	23	216
Average Hours per Updated ISP	0.5	1.3	0.5	1.3	0.6	0.8	0.3	0.4

CCNBC also uses a different service planning process than other sites. Service planning at CCNBC is a group process done in collaboration with the participant, the TBI Project service coordinator, and other service providers who will be working with the participant. Because OPTIONS offers a broad array of services for people with disabilities, the “other service providers” are often staff from other parts of CCNBC’s organization. Use of this larger collaborative process is reflected in the fact that the CCNBC project coordinator spends more time in developing initial ISPs than do staff from other sites.

The TBI Project fully anticipates that ISPs may be updated more than once per quarter. While all of the project sites update service plans when needed and appropriate, the sites take different approaches to updating participant ISPs. Clooney, for example, builds into the plan an individualized schedule for reviewing and updating the ISP that is most appropriate to each participant. CCNBC established that ISPs would be updated no less frequently than every six months. St. Jude just started doing formal ISPs last year, and both St. Jude and CCCIL update participant service plans every three to six months. In contrast, Pomeroy staff update participant ISPs every time they meet with participants.

As previously noted, the TBI Project sites are charged with providing a set of core services, which include community reintegration, supported living, vocational support, and service coordination. The remainder of this section discusses provision of these services, then ends with an overview of other services that the sites provide which are supported by TBI funding.

Community Reintegration Services

Community reintegration consists of “services needed by participants that are designed to develop, maintain, increase, or maximize independent functioning, with the goal of living in the community and participating in community life. These services may include, but are not limited to, providing or arranging for access to housing, transportation, medical care, rehabilitative therapies, day programs, chemical dependency recovery programs, personal assistance, and

education.”³ DMH directed the TBI Project sites to include under community reintegration referrals to and participation in community college programs that are primarily therapeutic, with the end goal not necessarily being a vocational one. On the assessment forms, site staff usually count these community college programs as day programs.

The quarterly site statistics do not provide an unduplicated count of participants who received each type of service; therefore we cannot calculate the proportion of all participants who received each type of service. Similarly, without the unduplicated count, the average total number of hours of each type of service that participants used over the course of a year cannot be calculated. We can, however, report the average total hours of each type of service that participants who used the service received per quarter.

Across all seven sites, participants used an average of four hours of community reintegration services per quarter. As Figure 4.4 shows, participants at CCNBC used substantially more of these services than their counterparts at the other sites. CCNBC’s grant covered the provision of individualized day program services to several individuals, which increased the average hours of services used for the site’s participants as a group. All of the other sites provided an average of less than ten hours of community reintegration services to participants..

Figure 4.4 Average Total Hours of Core Participant Services Provided Per Quarter*								
Average Hours per Participant per Quarter	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Community Reintegration Services	4.0	1.0	2.0	58.8	2.4	5.3	2.2	5.9
Supportive Living Services	3.5	1.8	2.1	13.2	7.7	5.3	1.1	2.6
Vocational Supportive Services	11.7	4.3	0.9	16.2	6.0	19.4	1.0	15.7
Service Coordination Services	1.9	1.0	1.6	6.6	2.7	2.9	1.4	4.2

* This figure reports the average hours of service provided per participant per quarter for each site. Because the site statistics do not provide an unduplicated count of participants who received each service across quarters, it is not possible to calculate the average per year.

Supported Living Services

Supported living services are designed to increase a participant’s independent living skills, and include supervision, support, and training in the participant’s place of residence or other setting (including the TBI Project site). During almost every site visit interview with TBI Project staff, respondents noted that differentiating between community reintegration and supported living

³ California Welfare and Institutions Code Section 4353-4359

services was difficult, particularly because supported living could be provided both in home and in other settings. As a result, some sites counted specific services as community reintegration, while others counted the same services as supported living.

Two of the sites have strong links to supported living programs in their local areas. OPTIONS operates a number of supported living residences in San Luis Obispo with funding primarily from the state Department of Developmental Services. Several of the site's participants live in these homes. In Orange County, St. Jude's project director helped establish a supported living apartment building for persons with TBI, funded by Section 8 and other sources. Again, a number of the site's participants reside there. Despite the availability of supported living services in both these communities, the two sites provided very different amounts of supported living assistance to TBI Project participants, as Figure 4.4 shows. CCNBC provided an average of 13 hours to each participant who used grant-funded supported living services per quarter, while St. Jude participants who accessed these services received an average of one hour per quarter. Clooney staff mentioned that they provide some participants with assistance in managing and paying their In-Home Support Service (IHSS) provider. Similarly, Headway staff reported making home visits to help participants organize their homes and to give coaching on time and money management.

Vocational Support Services

The TBI Project's vocational support services are targeted at individuals who are not served or are underserved by existing vocational rehabilitation services. The Welfare and Institutions Code distinguishes "vocational supportive services" from traditional vocational rehabilitation and day activity services using four characteristics:

- Service recipients appear to lack the potential for unassisted competitive employment;
- Ongoing training, supervision, and support services must be provided;
- The opportunity is designed to provide the same benefits that other persons receive from work, including an adequate income level, quality of working life, security, and mobility; and
- Flexibility in the provision of support, as necessary to enable the person to function effectively at the work-site.⁴

Across all of the sites, participants who used vocational support services received an average of about 12 hours of this type of assistance per quarter (see Figure 4.4). The two sites that currently are included under the DMH/DR cooperative agreement (Mercy and Pomeroy) provided a substantially higher average number of hours of vocational support per quarter than did the sites that were not covered by the agreement. CCNBC was negotiating the terms under which it would be included in the interagency agreement at the time of the site visit. Participants at this site used a similar amount of vocational support as the participants at Mercy and Pomeroy.

⁴ *ibid*

Service Coordination Services

As Figure 4.4 above illustrates, sites varied in the average number of hours of service coordination provided per quarter. For the purposes of computing TBI Project site statistics, service coordination can be any or all activities that occur once a participant has been accepted for services with the project site, beyond intake and assessment, community reintegration, supportive living, or vocational supportive services. Service coordination activities may include provision of information and resources for participants, advocacy, participant and family education about options, liaison for participants among service providers, problem-solving with participants, and monitoring and following-up on well-being and progress.

The TBI Project sites vary slightly in how they organize provision of service coordination. Clooney, CCCIL, Headway, and Pomeroy all have multiple service coordinators who each are responsible for their own participants. St. Jude staff, on the other hand, all work with all of the site's participants. Mercy and CCNBC each have only one service coordinator. The CCNBC service coordinator may not be a participant's primary case manager if the individual lives in one of the organization's residential facilities (see Chapter 2). Finally, while most of the sites provide the majority of their service coordination at one location, Pomeroy provides service coordination at two locations—the host organization's headquarters and St. Mary's Rehabilitation Center, a partner agency.

Other Services Funded By the TBI Grants

The TBI Project sites are charged with developing necessary programs and services to meet the needs of adults with traumatic brain injuries in their geographic service areas. The sites have indeed developed a variety of additional services for their TBI participants, to the extent that is possible given their limited funding. These additional services are not documented as a separate category of services for the purposes of calculating the quarterly site statistics, and are counted as provision of one of the core services.

As we described in Chapter 2, the two sites that are covered by the interagency agreement between DMH and DR have slightly more resources to devote to provision of vocational services. Mercy uses its DR funding to subcontract with Crossroads Employment Services for pre-employment services, job development, and job coaching. Pomeroy provides these services directly, through the organization's divisions outside of the TBI Project.

In line with the Project's goal to serve those most in need, Mercy also uses its TBI funding to provide regular outpatient rehabilitation services for TBI survivors without insurance. The site also benefits from being co-located in the outpatient rehabilitation center, and has used the center's occupational therapy areas to provide life skills courses tailored for people with traumatic brain injuries.

As part of the site's supported living services, Clooney staff provide money management assistance to participants. They also keep onsite copies of participants' important papers and records.

At the time of the evaluation's site visit, Making Headway staff were conducting a needs assessment among participants' families about their TBI education and support needs. The

resulting information will be used to design the curriculum for a “caregiver class” for family members.

As mentioned earlier in this chapter, CCNBC provides individualized day program services to participants, based totally in the local community. These services are provided in small groups, with a ratio no larger than one staff person to three participants. Instead of working within a classroom setting, the group takes public transit to run errands, get coffee, and visit the library and other public resources.

Services Used by the Evaluation Study Sample

While the previous section describes services provided to all participants during the fiscal year (regardless of when they enrolled in the program), the following section takes a slightly different look at services. Here we describe the services used specifically by the participants in the study sample (those that initially entered the program between February 1, 2003 and June 30, 2004). Using participant-level data, we examine the number of individuals who received each type of services.

The TBI Project assessment form collects information on the use of 11 types of service: service coordination; specialized evaluations; structured living assistance; mental health services; substance abuse program; social/recreational program; supported employment (pre-placement); supported employment (post-placement); employment services; educational services; and day program services.⁵ Site staff collect these data at six, 12, and 18 months after participants enter the program. Thus, the six-month assessment reports on services that participants receive between intake and six months, and the 12-month assessment summarizes services provided to participants between six and 12 months’ tenure in the program. Because of the relatively short time frame of the evaluation, none of the participants in the study sample were in the program long enough to complete an 18-month assessment.

This section first describes the services that the study sample used during their first six months of participation in the TBI Project. We then give an overview of services used between six and 12 months post-enrollment.

Services Used During the First Six Months of Participation

If participants had not been enrolled in the program long enough to complete a six-month assessment, no data were available on the services they used after intake. Given Making Headway’s implementation timeline, no participants from this site were enrolled in the program long enough to have completed a six-month assessment. Therefore, no data on use of services is available from this project site.⁶ Overall, information about the services that the study sample

⁵ No common definitions or instructions exist to aid site staff in completing the assessment form, thus it is not clear whether staff record use of these services only when the site provides the assistance directly, or whether they record receipt of a service regardless of who provides it.

⁶ Tables displaying more detailed information on participants in the study sample by TBI Project site are available in Appendix A-1: Supplemental Tables on Evaluation Sample.

used during their first six months as participants was available for 129 participants. This information is summarized in Figure 4.5.

Figure 4.5 Services Used Between Intake & Six Months: Proportion of Participants Who Used Each Type of Service (n = 129)								
	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Services Used	(n = 129)	(n = 53)	(n = 18)	(n = 8)	(n = 0)	(n = 22)	(n = 9)	(n = 20)
Service Coordination	99%	100%	100%	100%	-	96%	100%	100%
Specialized Evaluations	16%	6%	28%	25%	-	18%	22%	21%
Structured Living Assistance	19%	25%	17%	38%	-	5%	11%	16%
Mental Health Services	22%	28%	6%	25%	-	5%	11%	42%
Substance Abuse Program	9%	17%	11%	0%	-	0%	0%	0%
Social/ Recreational Program	40%	42%	56%	25%	-	27%	100%	16%
Supported Employment (Pre-Placement)	4%	4%	6%	0%	-	0%	0%	11%
Supported Employment (Post-Placement)	1%	2%	0%	0%	-	0%	0%	0%
Employment Services	15%	8%	11%	50%	-	5%	22%	32%
Educational Services	7%	0%	17%	13%	-	0%	22%	16%
Day Program	41%	49%	44%	25%	-	18%	22%	55%
Substance Abuse Help	12%	15%	11%	0%	-	0%	11%	20%

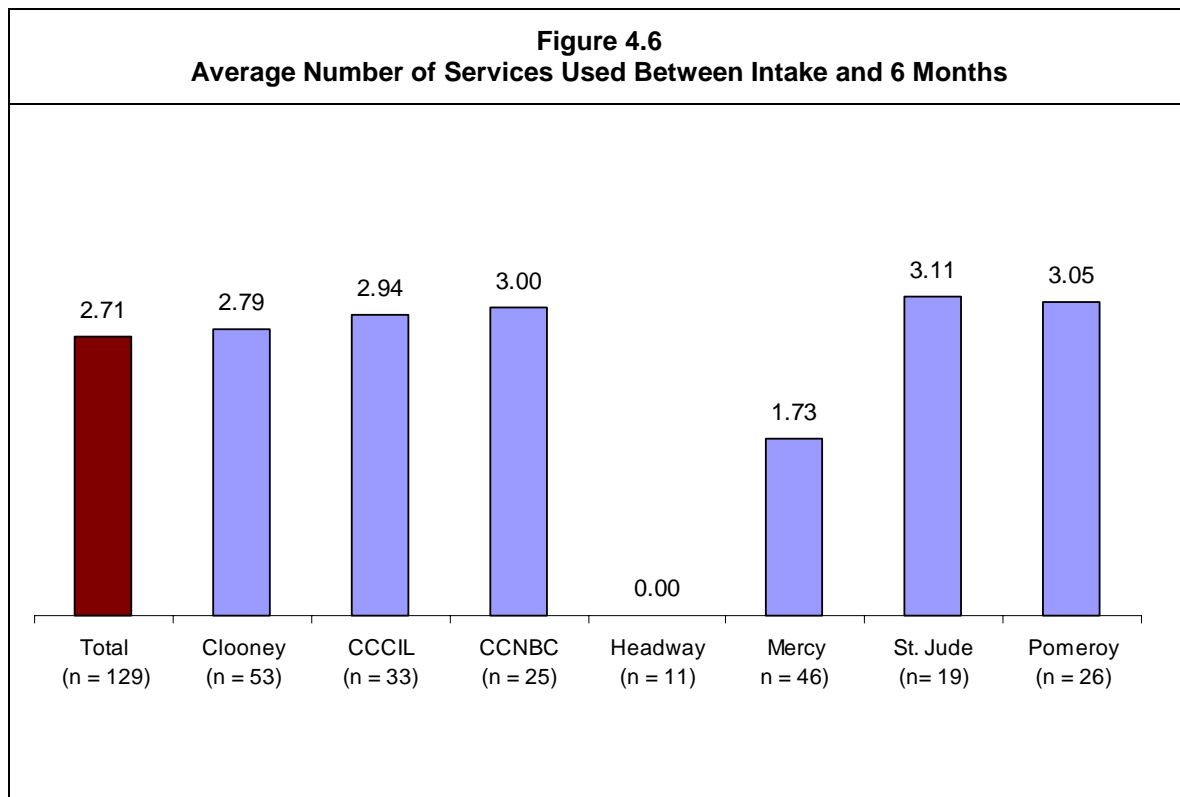
* None of Making Headway's participants had been in the program long enough to have six month assessments.

Because the TBI Project is designed to coordinate the provision of existing community-based services, it comes as no surprise that the virtually all participants received service coordination between intake and six months. The services that the participants, as a group, used most frequently after service coordination were day program and social/recreational services.

Across all sites, nearly half of participants had used day program services at six months (41%), but on a site-by-site basis this ranged from 55% to a low of 18%. Forty percent of all participants used social and recreational services between the time they enrolled in the program and their six-month assessment. St. Jude circulates to participants a monthly newsletter listing free and low

cost social and recreational activities available in the local area. This sharing of information and encouragement to join in no doubt contributes to the finding that all St. Jude participants were involved in social and recreational services.

Aside from service coordination, the services that participants used most frequently depended to some degree on whether they received services from one of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) or from a site that was funded more recently. For example, the four original sites provided day program and social/recreation services to more of their participants than did the newer sites. Unlike participants at the four original sites, however, CCNBC participants were more likely to use employment services and structured living assistance than they were to take part in a day program. Similarly, Pomeroy participants were more likely to use mental health services or employment services than they were to join in social or recreational activities. Both Pomeroy and CCNBC were DR vendors and established providers of vocational services to people with developmental disabilities before they joined the TBI Project. Thus, it is likely that they have naturally extended vocational services to their new participants with brain injury. These results mirror those presented in Figure 4.4, which showed that CCNBC and Pomeroy participants, along with Mercy participants, used substantially more hours of vocational support than did those served by other sites.



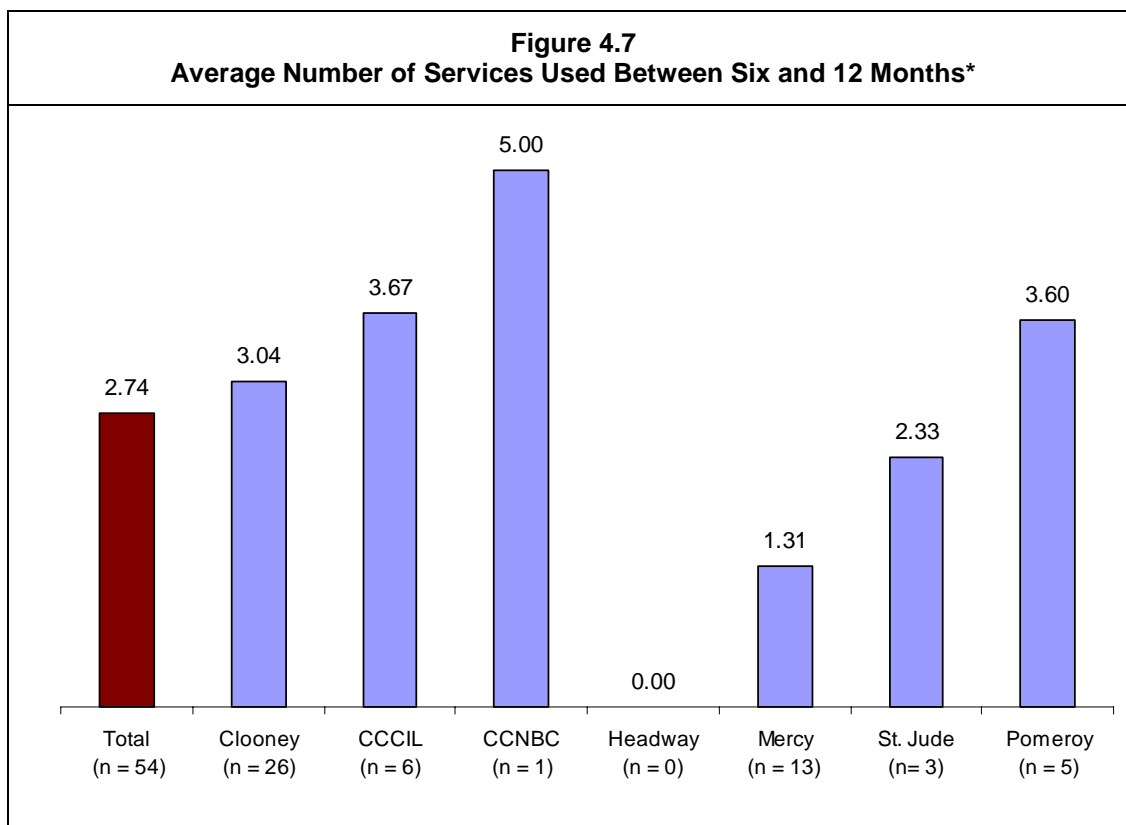
*Making Headway participants had not received services long enough to have completed six-month assessments.

Overall, across all the sites participants used an average of two types of services during their first six months in the program. As Figure 4.6 illustrates, the average number of services that participants used varied slightly by site. On average, Mercy participants used fewer different types of services than participants served by other sites.

Services Used Between Six and 12 Months After Enrollment

Information on services used between the six-month and 12-month assessments was available for 54 individuals. Nearly all participants continued to use service coordination during this period. Overall, the proportions of participants using each type of services remained fairly constant from six to 12 months. A slightly larger proportion were taking part in a day program at their 12-month assessment than they did at six months, while the percentage of participants joining in social and recreational activities remained unchanged from one period to the next.

The average number of types of services that participants as a group used stayed basically the same, although the proportions by site changed slightly for some sites (see Figure 4.7). For example, the average number of services that CCCIL participants used increased from their six-month to their 12-month assessments, while Pomeroy participants used slightly fewer services during their second six months of participation.



*Making Headway participants had not received services long enough to have completed six- or 12-month assessments.

The findings from the study sample's assessment data appear to show that participants make small changes, if any, in the types of services they use during their first year in the TBI Project.

In the following chapter we describe how the services provided to project participants addressed their needs, and the outcomes that have resulted from these services.

5. Participant Outcomes

In addition to describing TBI Project services and participants, the evaluation is charged with assessing two key types of participant outcomes:

- The degree of community reintegration achieved by participants, including their increased ability to independently carry out activities of daily living, increased participation in community life, and improved living arrangements; and
- The improvements in participants' prevocational and vocational abilities, educational attainment, and paid and volunteer job placements.

We examine these outcomes using three different types of data. First, all of the sites used the Community Integration Questionnaire (CIQ) to assess changes in participants' community integration at enrollment and at six-month intervals. Second, sites reported information on participants' educational, vocational and living situation status at enrollment and at six-month intervals as part of their assessment data. Finally, we also examine the extent to which sites provided services to address specific needs, and the extent to which these services appear to result in a reduction of those reported needs.

Because outcomes are measured by looking at progress over time, we report outcomes here only for the six centers for which we have follow-up data. (Making Headway began operation too recently to have conducted six-month assessments during the evaluation period.) This chapter discusses different samples of TBI Project participants in analyzing outcomes. The description of CIQ results focuses on scores for the six-month outcome sample (125 participants). The analysis of changes in vocational and educational status, and in living arrangements, also examines the 125-member six-month outcome sample. The last part of the chapter, analyzing the extent to which the project met specific participant needs, looks at the evaluation sample at intake, the six-month outcome sample, and the 12-month sample consisting of 49 participants.

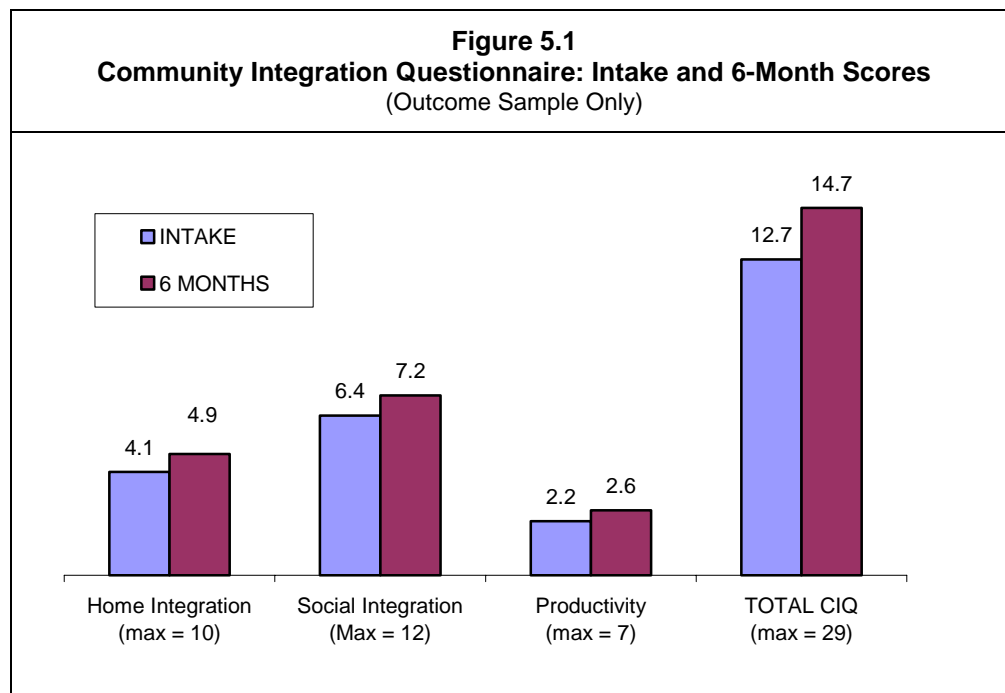
Change in Community Integration

The Community Integration Questionnaire (CIQ) was developed by a group of professionals and consumers who used the following design criteria: brevity; suitable for use in an in-person or telephone interview, preferably conducted with the TBI survivor him/herself (or with a proxy); focus on behaviors rather than feeling states; no biases resulting from age, gender or socioeconomic status; sensitive to a wide variety of living situations; and value neutral.

The CIQ consists of 15 items organized into three subscales, which allow an analysis of integration within specific domains of everyday life. The home integration subscale examines activities primarily related to the home, while the social integration subscale asks about social activities. The productivity subscales rate participation in activities such as education, vocational, or other productive activities outside the home.

The questionnaire is scored to provide totals for each subscale, as well as for community integration overall. The basis for scoring is primarily frequency of performing activities or roles, with secondary weight given to whether or not the subject completes activities independently or jointly with others, and the nature of these other persons (for example, with/without TBI). CIQ scores are not assigned specific values, but represent a level of integration relative to the maximum possible score for each subscale and for the total. A high score indicates greater integration, and a low score reflects less integration.

The evaluation's analysis of changes in CIQ outcomes uses data for those 125 individuals for whom project staff had completed six-month assessments.¹ Throughout this chapter, we refer to these participants as the "outcome sample." Figure 5.1 displays the average scores for the three subscales and the total CIQ score for the outcome sample at intake and at the six-month follow-up. On average, all three subscales and the total CIQ score were higher at the six-month follow-up than at intake. (A detailed table showing mean scores at intake and at the six- and 12-month assessments, along with computed changes in scores between follow-ups, can be found in Appendix A-1. Data from the 12-month assessments are not included in this discussion because the number of individuals for whom 12-month data were available is too small to warrant extensive analysis. Appendix A-1 shows, however, that the results at 12 months generally continue to reflect slow, steady improvement over time in the five TBI Project sites for which data are available.)



¹ None of Making Headway's participants had been enrolled in the project long enough to have completed a six-month assessment; thus this site is not included in this analysis.

This section examines changes in participants' community integration a little more closely by looking at differences across sites in subscale scores. Because the CIQ scores do not represent "categories" or levels of integration but a level of achievement relative to the maximum score, we have analyzed the proportional change in subscores and the total score over time. Readers should note that computing such measures from intake to the six-month assessment result in proportionally higher increases for individuals who had the lowest initial scores. Consequently, the proportional changes discussed below may not align with a simple computation of "percent increase" in scores based on the average scores at intake and six months later.

Home Integration

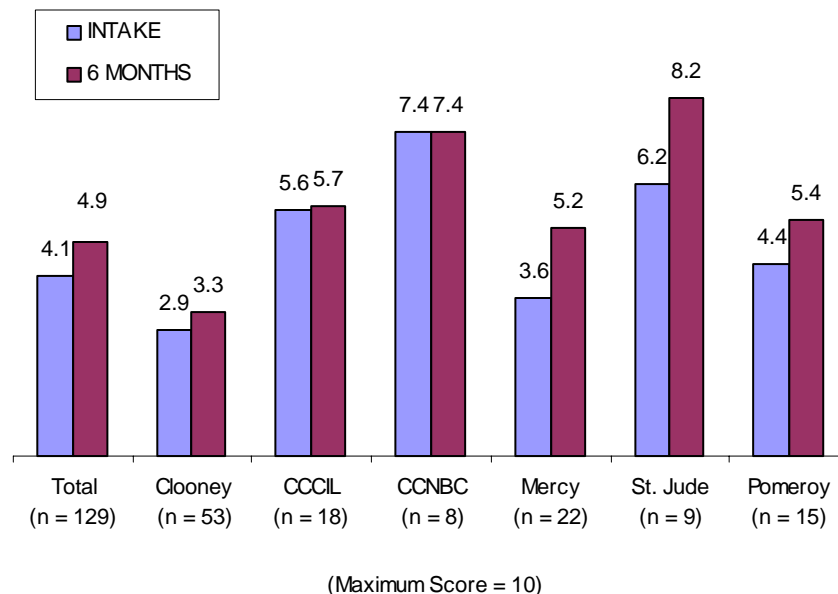
Figure 5.2 includes the five items that comprise the Home Integration Scale of the CIQ. The maximum score possible on the Home Integration scale is 10. Across all of the sites, as Figure 5.3 shows, the average Home Integration score at enrollment was 4.1, ranging from a low of 2.9 at Clooney to a high of 7.4 at CCNBC.

Figure 5.2
CIQ Home Integration Scale Questions

1. Who usually does shopping for groceries or other necessities in your household
2. Who usually prepares meals in your household?
3. In your home who usually does normal everyday housework?
4. Who usually cares for the children in your home? [N/A for children older than 17]
5. Who usually plans social arrangements such as get-togethers with family and friends?

[Answer Categories: Yourself alone; Yourself and someone else; Someone else]

Figure 5.3
Community Integration Questionnaire: Home Integration Scale
(Outcome Sample Only)



At the time of their six-month assessments, participants' Home Integration scores as a group averaged 4.9. This represents an average increase of 33% over the average Home Integration score at intake. Six-month Home Integration scores ranged from a low of 3.3 at Clooney to a high of 8.2 at St. Jude. With the exception of CCNBC and Pomeroy, the average Home Integration score for participants enrolled at each of the sites with six-month follow-up data increased over their intake scores. St. Jude participants experienced the largest average increase, representing 131% increase from intake to six months, followed by Mercy, with an average increase of 89%. On the other hand, average Home Integration subscores were the same at intake and six months for CCNBC participants.

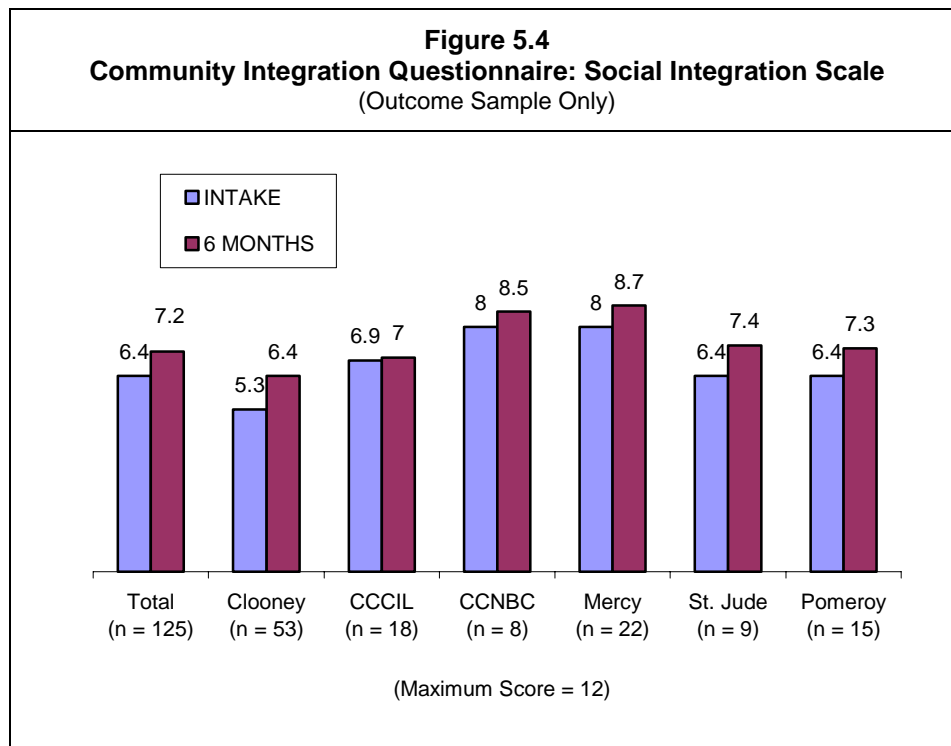
Social Integration

The CIQ's Social Integration Scale includes the following six items:

1. Who usually looks after your personal finances, such as banking or paying bills? [Yourself alone; Yourself and someone else; Someone else]
2. Approximately how many times a month do you now usually participate in shopping outside your home? [5 or more times; 1-4 times; Never]
3. Approximately how many times a month do you now usually participate in leisure activities such as movies, sports, restaurants, etc.? [5 or more times; 1-4 times; Never]
4. Approximately how many times a month do you now usually visit friends and relatives? [5 or more times; 1-4 times; Never]
5. When you participate in leisure activities do you usually do this alone or with others? [Family and friends; Friends without head injury; Mostly family; Mostly friends with head injury; Mostly alone]
6. Do you have a best friend with whom you confide? [Yes; No]

The maximum score possible on the Social Integration Scale is 12. As Figure 5.4 shows, the average Social Integration score for the outcome sample at enrollment was 6.4 and ranged from a low of 5.3 at Clooney to a high of 8.0 at CCNBC and Mercy.

At the time of their six-month assessments, participants' Social Integration scores averaged 7.2. This change represented a 22% increase in the average subscore overall. St. Jude participants experienced an increase of 93%, on average. Participants at the other sites showed smaller increases in their Social Integration scores, with CCCIL participants experiencing a proportionate average increase of less than one percent.



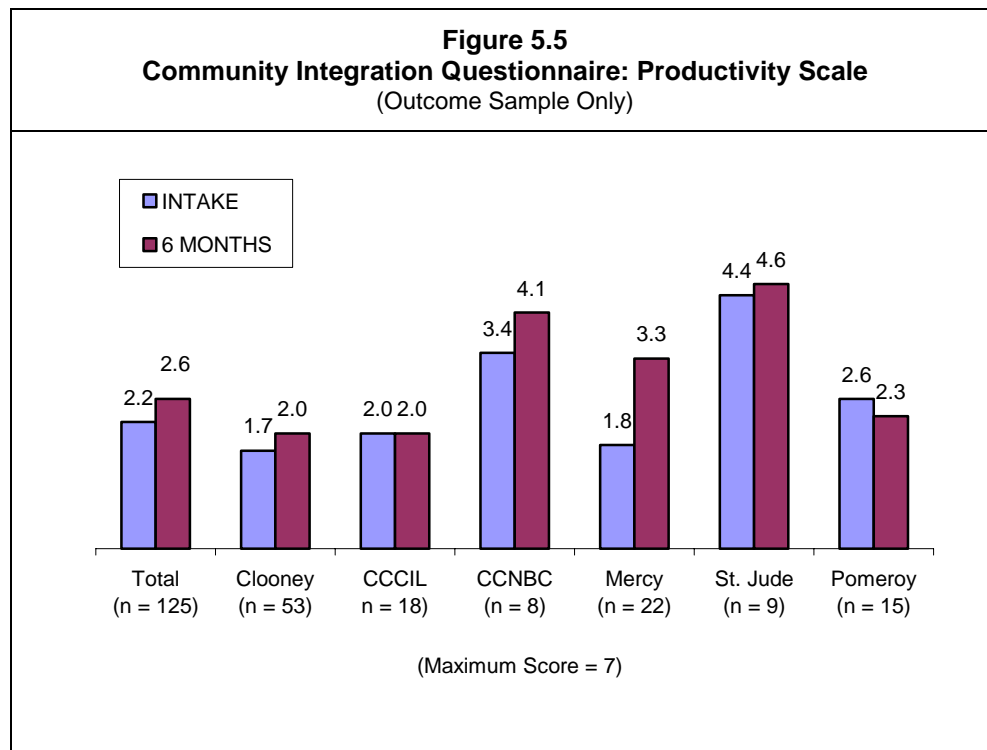
Productivity

The Productivity Scale of the CIQ consists of the following four items:

1. How often do you travel outside the home? [Almost every day; Almost every week; Seldom/never (less than once per week)]
2. Please choose the answer that best corresponds to your current (during the past month) work situation. [Full-time (more than 20 hours per week); Part-time (less than 20 hours per week); Not working, actively looking; Not working, not looking; N/A-Retired due to age]
3. Please choose the answer that best corresponds to your current (during the past month) school or training program. [Full-time program; Part-time program; No school/training; N/A-Retired due to age]
4. In the past month, how often did you engage in volunteer activities? [5 or more times; 1-4 times; Never]

The maximum score possible on the Productivity Scale is 7. As Figure 5.5 shows, the average Productivity score at enrollment across all of the sites was 2.2 and ranged from a low of 1.7 at Clooney to a high of 4.4 at St. Jude.

At the time of their six-month follow-ups, participants' Productivity score averaged 2.6 across the six sites. By site, Productivity scores at the six-month assessment ranged from a low of 2.0 at Clooney and CCCIL, to a high of 4.6 at St. Jude. The sole CCNBC participant with six-month



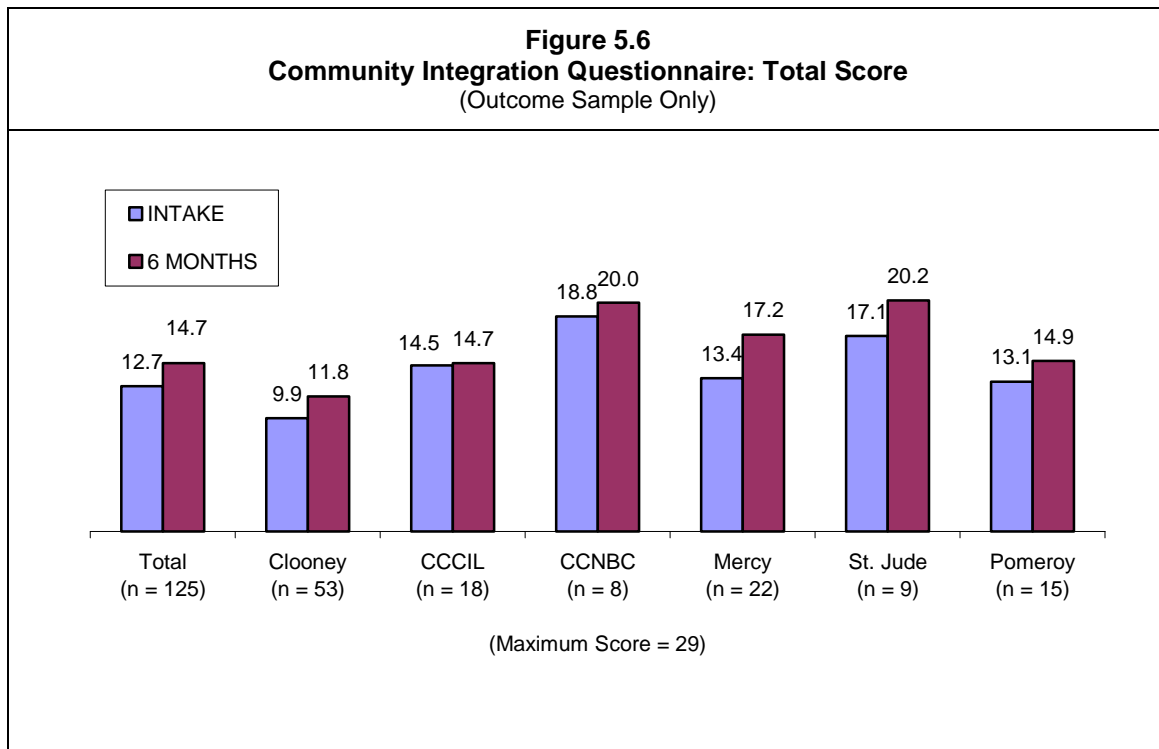
assessment data experienced the greatest change in this subscore, an increase of 150% from intake to six months. Mercy and St. Jude participants also experienced large proportionate increases in their Productivity scores from intake to six months, while Pomeroy participants' subscores declined by an average of one percent.

Total CIQ Score

The 15 items on the CIQ can also be combined into a single score with a maximum of 29 possible points. As Figure 5.6 shows, the average total CIQ score at enrollment across all of the sites was 12.7, and ranged from a low of 9.9 at Clooney to a high of 18.8 at CCNBC.

By their six-month assessments, participants' average total CIQ scores had increased to 14.7 across the six sites. Participants at St. Jude experienced an average increase of 92% in their total CIQ scores between intake and their six-month assessment, and Clooney participants' scores increased by 61%. The other sites' participants experienced smaller increases in their scores, ranging from less than one percent at CCCIL to 35% at Mercy.

These results confirm that individual survivors who enter the TBI Project are severely limited in all aspects of community integration. While the evaluation period may not be long enough to observe dramatic changes for most participants, program participation does seem to help participants improve their level of community integration over time.



Across all the sites, two-thirds of participants experienced a change in total CIQ score during their first six months in the program. Because those who experienced a positive change tended to be individuals who had relatively low CIQ scores at intake (and therefore those who could most benefit from project services), this increase represented an average 64% increase over their initial total scores.

Figure 5.7 Total Increase in CIQ Scores		
Increase in Total CIQ Score	Participants With Increase	
	N	%
Six Months (n = 125) <ul style="list-style-type: none"> Any increase Average Proportionate Increase in Score from Intake to Six Months 	67	54% 79.8%
12 Months (n = 51) <ul style="list-style-type: none"> Any increase Average Proportionate Increase in Score from Intake to 12 Months 	33	65% 74.4%

Figure 5.7 shows the number and proportion of participants in the outcome sample who had an increase in CIQ scores over the course of the evaluation's observation period. Just over half of the outcome sample had an increase in the first six months, and their average total CIQ scores increased by 79.8% from intake to six months. Similarly, two-thirds of the individuals in the 12-month outcome group experienced an increase in total CIQ score by one year post-enrollment and, on average, their scores increased by 74% during this period. It is important to note that the 12-month observation data probably undercounts the total change, given that data on 12-month assessments were only available for 40% of the 125 participants in the outcome sample.

Change in Vocational and Educational Attainment and Living Arrangements

In addition to the CIQ, sites reported outcome data in a number of other areas. Using information reported on day and vocational program participation, education and employment status, and income and living situation, we summarized positive and negative outcomes across seven different domains as illustrated in Figure 5.8. Positive outcomes included: entering or increasing days per week in a day program; entering or maintaining participation in vocational services,

Figure 5.8 Definitions of Positive and Negative Participant Outcomes			
Outcome Domain	Positive Outcome	Negative Outcome	Either Positive or Negative Depending on Circumstances
Day Services	<ul style="list-style-type: none"> Entered day program Increased days per week 	<ul style="list-style-type: none"> Decreased days per week Left day program 	
Vocational Services	<ul style="list-style-type: none"> Entered vocational program Maintained participation Became DR client 	<ul style="list-style-type: none"> Left vocational program without job 	<ul style="list-style-type: none"> Left DR
Education	<ul style="list-style-type: none"> High school degree/GED to some college Some college to AA degree BA to some graduate school 		
Employment	<ul style="list-style-type: none"> Maintained employment Obtained employment 	<ul style="list-style-type: none"> Stopped working 	
Income	<ul style="list-style-type: none"> None/General Assistance to SSI/DI None to General Assistance Family to SSI/DI SDI to SSI/DI Moved to employment SDI to pension 	<ul style="list-style-type: none"> Moved to family support 	
Living Situation	<ul style="list-style-type: none"> Family to Alone/Dependent child Homeless to not homeless Facility to friend or alone 	<ul style="list-style-type: none"> Family/spouse to facility 	<ul style="list-style-type: none"> Family/spouse to friend/roommate Alone to friend/roommate
Program Termination	<ul style="list-style-type: none"> Goal met 	<ul style="list-style-type: none"> No contact No follow-through 	<ul style="list-style-type: none"> Moved Participant choice

including becoming a DR client; increasing educational attainment from one of the educational levels used on the assessment form to another; obtaining or maintaining employment; moving from no income to some income, or from an unstable source to a stable source of income; moving out of an institution, moving into a home from being homeless, or living alone or with dependent children after living with parents or other family members; and terminating from the TBI Project with needs met.

Negative outcomes were, for the most part, the inverse of those we identified as positive. These included: decreasing participation in or leaving a day program without entering employment; leaving a vocational program without entering employment; leaving employment; moving into a dependent situation with family members; moving into a skilled nursing or other supervised facility; and terminating from the project because of no contact or follow-through.

A few of the changes that participants experienced could be interpreted as either positive or negative, depending upon the individual's circumstances. These included: leaving DR; moving either from living alone or with family to sharing with a friend or roommate; and terminating from the program because of moving away from the area; and or participant choice. Because information about the circumstances of individual participants was not available, we omitted these changes from our analysis.

In the sections that follow, we present our findings about participant achievement of positive and negative outcomes.

Positive Outcomes

As shown in Figure 5.9, 72% of the 129 participants in the outcome sample experienced at least one positive outcome during the study period.² The most frequent area of gain—other than in CIQ score—was in day program participation. One-third of the sample entered some kind of a day program during their first six months of program participation. (See the discussion of services in Chapter 4 for more information about day program participation.) The second most frequent area of positive outcome was source of income, with 16% of the sample changing to a more independent and/or stable source of income. Employment outcomes combined both maintaining employment (8%) and obtaining employment (6%) for a total of 14% with positive employment outcomes. An additional 12% of the sample entered a vocational program or became a DR client.

² Appendix A-1 provides additional information including additional results for each site.

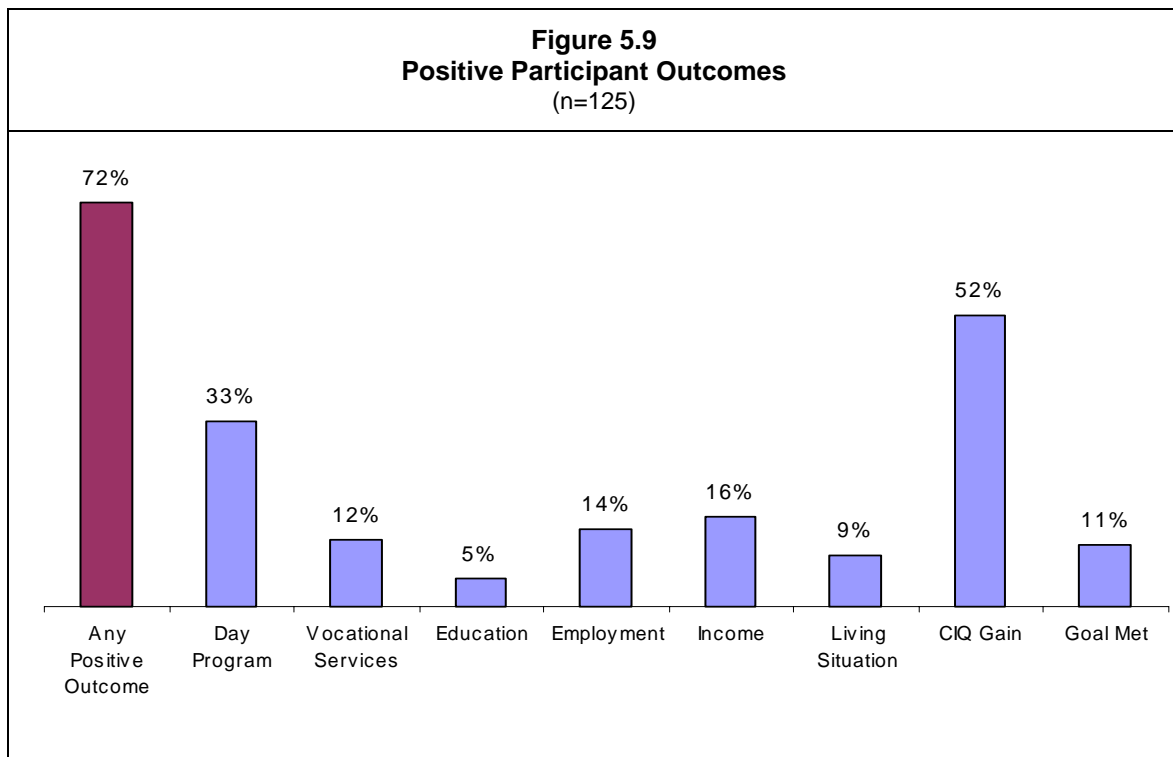
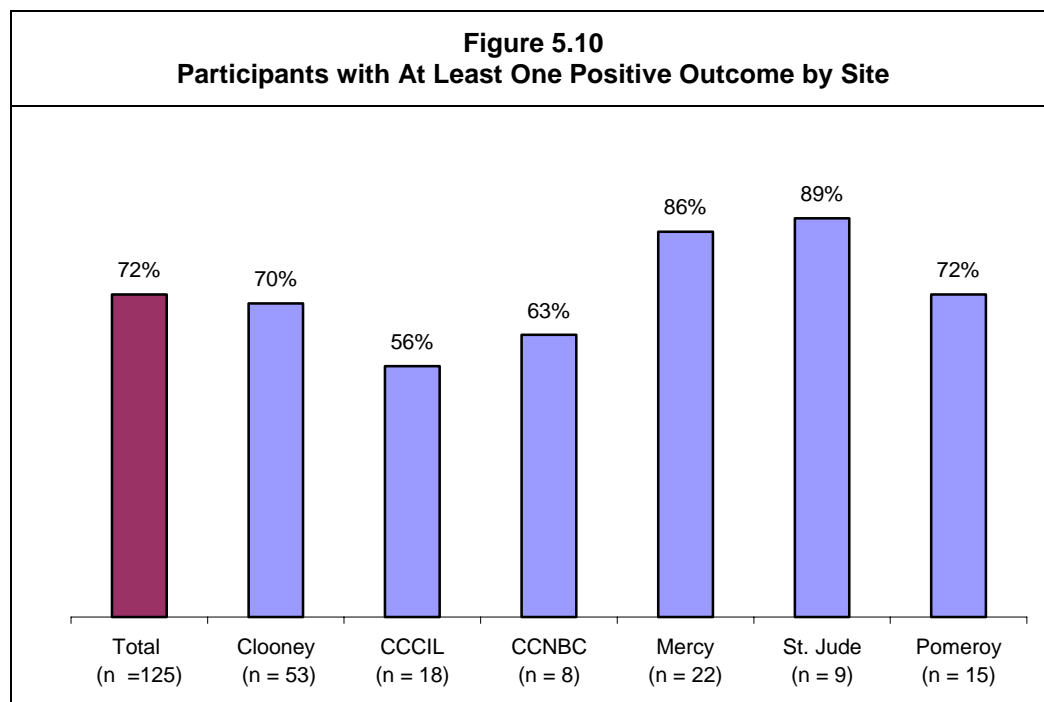


Figure 5.10 shows the variation in positive outcomes by site. Every site had positive outcomes for the majority of their participants in the outcome sample. St. Jude had at least one positive outcome for 89% of their participants, followed by Mercy at 86%. CCCIL was at the low end of the scale with at least one positive outcome for 56% of their participants.



Negative Outcomes

No discussion of program outcomes would be complete without assessing the extent to which participants were not successful or actually showed declines in status during program participation. These do not necessarily reflect program weaknesses, since we have no way of knowing what declines participants may have had in the absence of program services. Nonetheless, examining such outcomes is an important part of a complete description of participant outcomes.

As shown in Figure 5.11, about 20% of the 125 participants in the outcome sample had at least one type of negative outcome. This does not necessarily mean the program did not benefit them, however, as 73 % of them (all but seven individuals) also had at least one positive outcome.

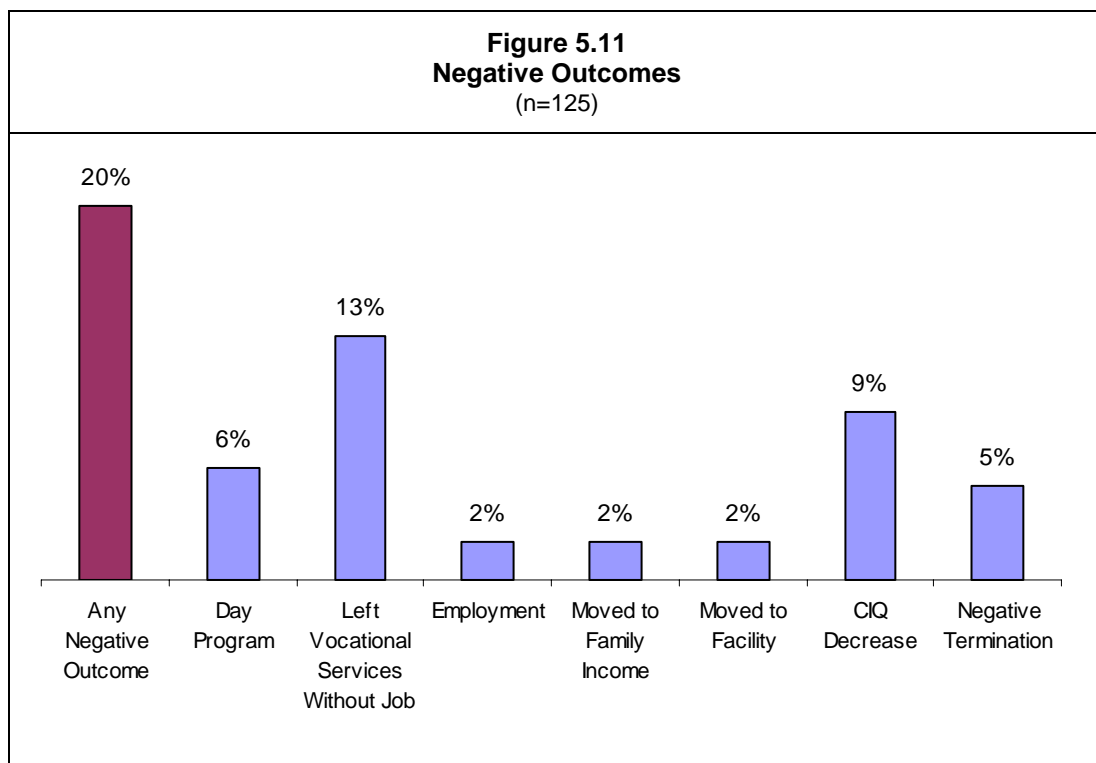
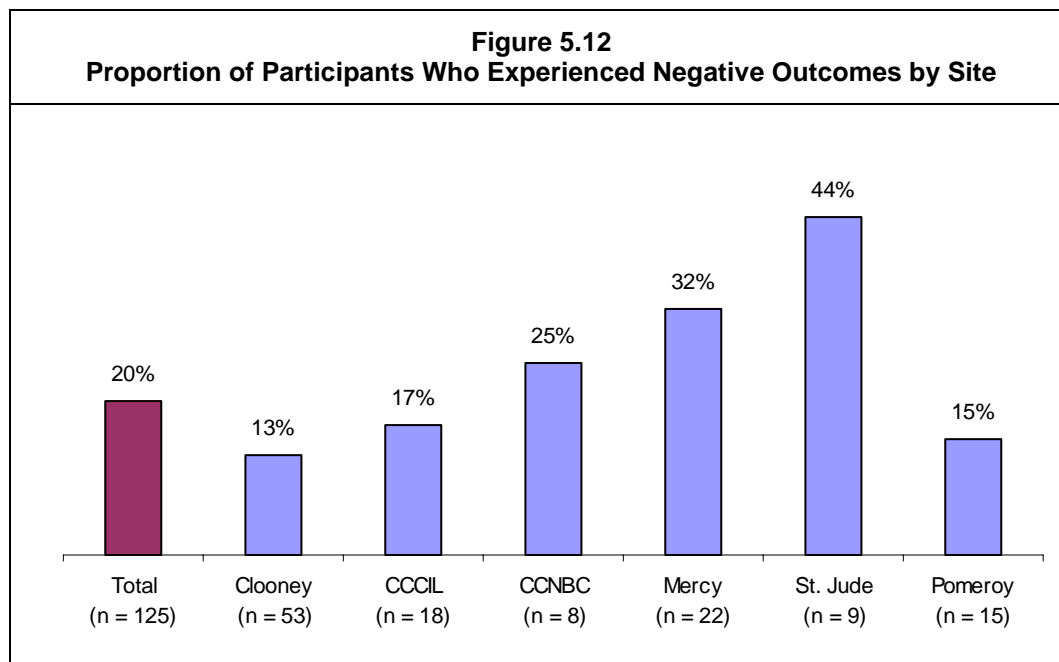


Figure 5.12 shows the variation in negative outcomes across sites. The sites with negative outcomes for the largest number of participants was St. Jude (44%), which is interesting considering it was also the site with the largest number of participants who had at least one positive outcome. The fact that St. Jude had the smallest number of participants in the data sample (only nine) is an important factor to consider when looking at the proportion of its participants with positive and negative outcomes. With such a small number of participants, a difference of only one or two participants substantially changes the average percentage for the site. The site with the fewest participants who experienced negative outcomes was Clooney (13%), which also had the largest number of participants in the sample.



Impact of Services on Needs

The TBI Project's assessment form collects information about participants' service needs at intake and at the six- and 12-month follow-ups. The six- and 12-month assessments also gather data about receipt of services. Collecting data on both service needs and receipt of services would allow for an assessment of whether participants' identified needs are met by the services that sites provide. Unfortunately, the assessment form tracks the receipt of services for only a fraction of the needs identified at each data collection point (see Figure 5.13). Further, items on the list of services provided do not directly align with items on the list of service needs, thus assessing whether a site met identified participant needs is difficult, if not impossible, in many cases. Finally, participant needs could be met either by sites providing services directly or by referring participants to other providers, so there would be no expectation that all of the identified needs would be addressed directly by project services.

Even without a perfect match between all identified needs and services provided; two types of analysis offer insights into the extent to which the project successfully addressed participants' needs. First, an analysis of how needs change over time offers a possible indication that individuals' needs may have been met. Second, while an item-by-item match between needs and services is not possible, several program services listed on the assessment form do match well with specific presenting needs. We investigated the relationship between the following pairs of services and needs:

- Mental health services (need for counseling);

Figure 5.13
Presenting Problem vs. Services Received

41. What are the participant's present needs? <i>(Check all that apply)</i>	44. What services has participant received? <i>(Check all that apply)</i>
(1) Day Program	Service Coordination
(2) Housing Assistance	Specialized Evaluations
(3) Counseling	Structured Living Assistance
(4) Transportation	Mental Health Services
(5) Medical Services/Testing	Substance Abuse Program
(6) Immigration Assistance	Social/Recreational Program
(7) ESL Classes/Education	Supported Employment (Pre-placement)
(8) Recreation	Supported Employment (Post-placement)
(9) Vocational Rehabilitation	Employment Services
(10) Social Security	Educational Services
(11) Community Education	
(12) Independ. Living Skills	
(13) Advocacy	
(14) Protective Services	
(15) Hygiene/Grooming	
(16) Funding Resources	
(17) Crisis Intervention	
(18) In-Home Assistance	
(19) Substance Abuse	
(20) Legal Issues	
(21) Respite Care	
(22) Aide Training	
(23) Budgeting	
(24) Self Help/Sup. Groups	
(25) NeuroPsych Testing	
(26) Other	

- Substance abuse program (need for substance abuse treatment services). This information is also collected in another data item on the assessment form that indicates whether participants are getting help for substance abuse (which may include private counseling or self-help groups such as AA in lieu of a formal treatment program);
- Social/Recreation Program (need for recreation);
- Employment services, supported employment, and/or educational services (need for vocational rehabilitation). Another question collects information about whether the participant is a DR client.
- Information about participation in a day program is not included in the above list of services a participant may have received, but is collected elsewhere in the assessment form, under day program participation (need for day program).

The figures below examine whether TBI Project participants received services that correlated with their identified needs. First, we summarize the proportion of participants who were reported to need the services listed above at each assessment and how much that changed over time. Then, we assess whether needs identified at intake were met by provision of corresponding services by the time of the six-month follow-up. Similarly, we looked at whether the services that participants received between the six- and 12-month follow-ups addressed the needs that had been identified at the six-month assessment.

Change in Service Needs Over Time

Across all services included in the assessment form's list of presenting needs, the proportion of participants who needed each service declined from intake to six months (see Appendix A-1). Figure 5.14 presents the proportion of participants with each of the five presenting needs listed above, as documented at intake, the six-month assessment, and the 12-month assessment. Over time, the proportion of participants who needed all but one service declined. As the figure shows, the percentage of individuals who needed day program, counseling, and vocational rehabilitation each decreased by at least 10% from intake to the 12-month assessment. The proportion that needed recreation/social services declined even more, by 22%.

Substance abuse treatment was the only service for which participants' need for services appears to have increased from intake to 12 months, although the increase was only 4%.

Figure 5.14 also presents the change from intake to 12 months in participant use of day program and DR services. Enrollment in day program services increased by over one-third (36%) during this period, while 18% more participants were DR clients at 12 months than at program enrollment.

Figure 5.14 Proportion of Customers with Presenting Need at Intake vs. Follow-up				
Presenting Need	Intake (n = 213)	6 Months (n = 130)	12 Months (n = 54)	% Change Intake to 12 Mo F-Up
Day Program	29%	23%	19%	-10%
Counseling	45%	42%	32%	-13%
Substance Abuse Treatment	9%	7%	13%	+4%
Recreation	26%	9%	4%	-22%
Vocational Rehabilitation	40%	35%	28%	-12%
Enrolled in Corresponding Service				
Enrolled Day Program	16%	41%	52%	+36%
DR Client	22%	31%	40%	+18%

Match Between Needs and Services

Our second analytic approach examined the match between service needs identified for each participant, and whether he or she received services to meet those needs. We focused on participants identified as needing each of the five types of services at intake, and determined the number of individuals for whom six-month assessment data were available. We then looked at the proportion of these participants who received the relevant services between intake and six months. Our analysis repeated this process using needs that project staff identified during participants' six-month assessments and services provided between their six- and 12-month assessments.

For all but mental health needs and services, a majority of participants who needed a service at intake had received it by their six-month assessment. As Figure 5.15 illustrates, almost two-thirds of participants who needed a day program and over half of individuals who needed recreation services had received those services by six months after program enrollment. Almost three-quarters of those who needed substance abuse treatment had received it within six months. In contrast, only 30% of individuals needing counseling at intake had received mental health services by the time of their six-month assessments.

Figure 5.15 Comparison of Need for Service with Subsequent Receipt of Services Intake to Six Months, and Six to 12 Months				
Presenting Need (Service Received)	Six Month (n=129)		12 Month (n = 52)	
	# Need @ Intake w/6 Mo Data	% Received Service @ 6 Mos	# Need @ 6 Mo w/12 Mo Data	% Received Service @ 12 Mos
Counseling (Mental Health Services)	66	30%	22	36%
Day Program (Day Program)	49	63%	15	87%
Recreation (Social/Recreation Program)	36	58%	4	75%
Vocational Rehabilitation (DR Client)	43	65%	21	71%
Vocational Rehabilitation (Employment Services)	49	33%	21	33%
Vocational Rehabilitation (Any Voc-Related Service Listed)	49	43%	21	33%
Substance Abuse Treatment (Substance Abuse Program)	11	73%	6	33%
Substance Abuse Help (From TBI Project)	11	82%	5	80%

Figure 5.15 presents three different services or service mixes that could potentially meet a participant's need for vocational rehabilitation services: DR services, employment services provided by another vocational service provider, and any combination of employment, supported employment, or educational services. Two-thirds of those who needed vocational rehabilitation services at intake were enrolled as DR clients by their six-month assessment. In contrast, much smaller proportions of TBI Project participants received vocational or employment-related services from other sources. Only one-third of participants who needed vocational rehabilitation services at intake had received employment services by the time of their six-month assessment, while 43% had received any type of vocationally-related service from the program—including employment services, supported employment, and educational services. This pattern continued through the 12-month assessment.

We examined two types of substance abuse services that participants could use: substance abuse treatment and substance abuse help. The majority of participants identified as needing assistance with either alcohol or drug abuse at intake had received both “help” for substance abuse as well as services from a formal substance abuse treatment program within their first six months in the program.

The majority of participants whom project staff identified as needing counseling, day program, social/recreation, and vocational rehabilitation services during their six-month assessments had received corresponding services by the time of their 12-month assessments. In fact, the proportion of participants whose needs were met increased during the six- to 12-month post-enrollment period for these four types of service needs.

On the other hand, the proportion of participants who needed substance abuse treatment and received it appeared to decrease between the six-month and 12-month assessments. Only one-third of those whom staff identified as needing these services at six months had received them by 12 months, compared to 73% of participants who had their need for substance abuse help or treatment met at six months.

Overall, based on these findings, participant’s needs for specific types of services seem to have decreased over time as they participated in the program. Either directly or indirectly, the TBI Project sites appear to have addressed participant needs for specific services, including social/recreation services, day programs, vocational rehabilitation, and substance abuse help or treatment. Further, the proportion of participants needing services who subsequently received those services increased over time for almost all types of assistance that we examined.

Summary

This chapter has assessed the impact of TBI Project services on participants using several different measures, and shown that, overall, participants have benefited from their involvement with the project. Across all the sites, participants’ scores on the CIQ showed increases over the period from intake to six months. Individual sites, however, showed larger gains in CIQ scores for particular subscales. Thus, most participants experienced at least some improvement in community reintegration after enrolling in the project.

Almost three-quarters of participants for whom data were available at six months had at least one positive outcome, while only 20% experienced at least one negative outcome. Further, a majority of participants at each of the sites experienced at least one positive outcome.

Using the needs identification tool included in the common assessment form, we found that across all participants, from intake to six months the proportion of participants who needed each type of service decreased. Finally, where the TBI Project assessment form documented services that specifically addressed needs listed in the form, the majority of participants who were identified as needing a service at intake had received the corresponding service by their six-month follow-up.

6. Customer Satisfaction

The California Welfare and Institutions Code Section 4353-4359 requires that the TBI Project evaluation include an assessment of participant and family satisfaction with services provided by the sites. The evaluation measured customer satisfaction among TBI Project participants in two ways. First, we conducted a mail survey of participants to gauge whether or not the services provided by the sites fulfilled their needs. Second, the surveys were supplemented with interviews with both participants and their family members completed during visits to each of the sites.

Participant Satisfaction Survey

Design of the evaluation's participant satisfaction survey instrument was based on the customer satisfaction measures already being used by most of the sites. The final version was developed in collaboration with the site project directors, with the goal of producing an instrument that would be easy to complete and thus would promote a high response rate from participants. The survey instrument was designed to be completed by participants, although family or caregivers could complete the survey on behalf of participants who were not able to complete the survey independently. Project staff were not permitted to assist participants in completing the survey.

Figure 6.1
TBI Project Participant Satisfaction Survey Questions

1. I was treated with respect.
2. I received the information and assistance I needed.
3. I was given information clearly and in a way I could understand.
4. Services were planned with my goals and needs in mind.
5. As a result of the services I received, I deal more effectively with daily problems.
6. I am better able to control my life since participating in the program.
7. If I needed to, I would be willing to use program services again.
8. I would recommend this program to other TBI survivors.
9. Overall, the assistance I received was: excellent; good; fair; poor; unacceptable.

Figure 6.2 Participant Satisfaction Survey: Rate of Return		
Site	Surveys Sent	Return Rate
Clooney	112	13%
CCCIL	41	37%
CCNBC	23	65%
Headway	43	51%
Mercy	49	37%
St. Jude	82	61%
Pomeroy	52	48%
TOTAL	402	40%

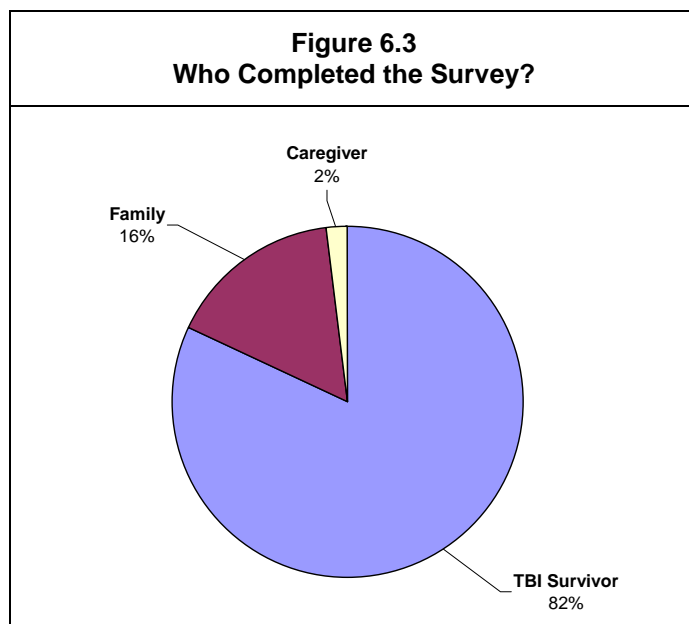
The survey consisted of nine questions probing the overall experience of participants (see Figure 6.1). Participants answered eight of the questions using a five-point Likert scale, with answers ranging from ‘strongly agree’ to ‘strongly disagree.’ The final question asked participants to rate their overall assessment of the help they received with a five-point Likert scale with answers ranging from ‘excellent’ to ‘unacceptable.’

Each site sent surveys to participants who were active on May 1, 2004. Staff mailed a total of 402 surveys across the seven sites. Sites mailed the survey along with a cover letter that stressed that the evaluation would maintain the confidentiality of survey responses. To raise the survey’s response rate, site staff made follow-up phone calls to remind participants to complete and return the surveys.

As Figure 6.2 illustrates, a total of 160¹ participant satisfaction surveys were completed across all sites, for a return rate of 40%. CCNBC had the highest rate of return with 65% of participants returning the survey. Clooney had the lowest rate of return (13%). Because Clooney sent out the largest number of surveys, however, the actual number of this site’s participants who returned their surveys was higher than the number received from participants of the other sites.

By and large, participants completed the surveys by themselves (82%). Figure 6.3 shows that of the surveys completed by non-participants, a member of the participant’s family completed 16% of the surveys, while the participant’s caregiver completed 2%. Clooney participants were most likely to complete the questions with assistance (43%), while all of CCCIL participants completed the survey independently.

The remainder of this section gives an overview of participants’ responses to the survey questions listed in Figure 6.1. Tables displaying more detailed information on responses to the Participant Satisfaction Survey for all seven of the TBI Project sites are available in Appendix A-2, “Supplemental Table on Participant Satisfaction Survey.”



¹ One survey was dropped due the fact that the participant’s site was unidentifiable.

Survey Results Overall

As Figure 6.4 shows, over three-quarters of participants strongly agreed with the statement: “I was treated with respect” (78%). Another 18% agreed with the statement, for a total of 95% of survey respondents who felt respected by project staff. Only three respondents disagreed with the statement, and these individuals strongly disagreed. Two of these participants offered comments that suggested that a miscommunication occurred with staff about the level of assertiveness and follow-through that the sites expected of participants.

Figure 6.4 Results of Participant Satisfaction Survey (n = 160)					
Survey Question	Strongly Agree	Agree	Neither Agree/ Disagree	Disagree	Strongly Disagree
Treated with respect	78%	18%	3%	0%	2%
Received information and assistance	65%	23%	9%	1%	1%
Information clear and understandable	64%	31%	5%	1%	1%
Services matched my goals	57%	29%	10%	3%	1%
Services helped with daily problems	53%	26%	15%	5%	1%
Better able to control my life	55%	23%	18%	4%	0%
Willing to use services again	69%	23%	5%	2%	1%
Would recommend to others	78%	16%	3%	2%	1%
	Excellent	Good	Fair	Poor	Unacceptable
Rating overall service	75%	14%	9%	2%	1%

The vast majority of respondents agreed that the sites provided the information and assistance they needed. Nearly two-thirds of participants strongly agreed with the statement and another 23% agreed. One participant wrote on his survey, “I have [received] excellent information from this program. They have helped me with so much. They’re always keeping me/us up about community programs and referrals that I really need.” Respondents also valued the manner in which information was communicated to them. Almost two-thirds strongly agreed with the statement: “I was given information clearly and in a way I could understand,” and another third agreed with the statement. A Southern California participant commented, “Without the sensitive and expert resourcing of [the

site's] employees I would definitely be a disenfranchised senior disabled person. I am so blessed to have [the project] as a stabilizing force of function."

"One thing I know for sure...TBI is a unique situation that is best understood and helped by either people who know it well from long experience or from folks who have one themselves... It is not a situation that can be helped by just anyone due to its uniqueness. The special care and people are very needed."

Across all the sites, 57% of participants strongly agreed with the statement: "Services were planned with my goals and needs in mind." Another 29% of participants agreed, bringing the overall total that agreed to 86% of respondents. One respondent noted, "This has been the missing link in rehab. TBI is invisible at times for some. This program assists you in every aspect of life. Helps you understand when you need it the most. They are wonderful angels. Assists you—two brains are better than one!" Another participant wrote, "Since I have been receiving assistance through [the program] my life has made great progress in such wonderful ways. I couldn't even begin to express the many ways that [the program] has been there for me, supported me or just in general helped me." A third stated, "Since my accident [the TBI Project] is "mission control" part of my life."

Over three-quarters of the survey respondents felt that TBI Project services had helped them deal more effectively with daily problems, and over half (53%) strongly agreed with the statement. One participant stated, "Over the years I've been part of the program, the encouragement, the advice, the financial support and the friendly voice of the staff have been consistently there for me. It has helped me out with my memory, my marriage and my life." Another respondent noted, "People with TBI have a difficult if not impossible time connecting with other people (socially) in all areas; interpersonally, career wise. [The program] helps me leap that gap to an unimagined extent. Without [it] my struggles would be vastly more difficult and perplexing."

Over half of participants strongly agreed with the statement: "I am better able to control my life since participating in the program," while another 23% agreed. Respondents were most ambivalent about the program's impact. Of all the survey questions, this one had the largest proportion (18%) of participants answering that they neither agreed nor disagreed with the statement. Nevertheless, participants from almost every site contributed comments that expressed their appreciation for the program's help in this regard. One participant wrote, "Thanks to the [program] I feel I've gone from totally dependent on society to becoming a contributor to society. I still have my limitations, but at least I recognize them and can deal with them." Other comments included, "This has helped my stress level a great deal," "I don't feel as helpless and lost since participating in this program," and "[The TBI Project] raised my self-esteem and also helped me get back on my feet. I cannot thank them enough."

"I'm a 48-year-old TBI survivor. This coming October 20, it will be 30 years since I had my auto accident and TBI. If [the program] had been around then, I might not have had as many problems re-entering society and the workforce. I also might have gotten SSI a lot sooner! It took over 20 years for me to get it!!! Thanks to some legal help, and [the program]. If I'd gotten it sooner, I could be watching my daughter grow up and possibly still married!"

Almost all (92%) of the survey respondents agreed that "If I needed to, I would be willing to use program services again," and most (69%) strongly agreed with the statement. Given that over one-quarter of participants served during the most recent fiscal year had been involved with the TBI

Project for over two years, it would appear that many participants have continued to use program services again and again. Many comments on the survey echoed the opinion; “They always help me whenever I call.”

More than three-quarters of participants strongly agreed with the statement, “I would recommend this program to other TBI survivors,” and another 16% of respondents agreed. One participant stated, “Everyone in the communities should know about this program and the help it provides. You never know when it might be needed...everyone should be aware it exists.”

Peer Counselor

I just want to fill you in,
on what other could not even begin,
she's there for me,
perhaps I just need someone to listen,
patiently,
someone that can understand me, she's my
peer,
she's one that's got it in gear,
she can see what's going on inside, and she
supports me on my ride, advocate, we share
a laugh, intercessor, she pleads on my behalf,
her love flows to me, so naturally, fully
cognizant of trauma to the head,
she's helped me to weave my own little web,
she's helped me through some hard times it
seems,
she's even pointed me to getting my dreams,
she can usually read if something is wrong
with me,
with goals, objectives and love, she
intervenes,
her peer support has come to mean so much,
and so many people her job does touch.

– Submitted with survey by TBI Project
Participant

Three-quarters of those who responded to the participant survey rated the assistance they received from a TBI Project site as “excellent,” and another 14% rated the assistance as “good.” A small proportion (9%) rated the assistance as “fair.”

Only 15 respondents (9% of the sample) replied negatively to any one of the survey questions. The majority of these participants responded negatively to two or more questions, however, none answered every question negatively. Of this group, five provided written comments that provided an idea as to the source of their dissatisfaction with the services they received. Three respondents felt that program services were designed around TBI as a disability instead of around them as individuals. The most articulate of these commented, “I feel that this program does not look at the individual. It concentrates on the definition of the disability not the individual. It does not raise expectations; it concentrates on the status quo. If expectations are the status quo the individual will only rise to that level.” Another respondent felt that the program had provided him with some information, but that he had never really received services. The last participant in this group was disappointed that she was dropped

from the program via a letter. She wrote that, “I still need help but I have no place to go and I couldn’t advocate for myself.”

The question that received the most negative responses was “As a result of the services I received, I deal more effectively with daily problems.” Nine respondents either disagreed or strongly disagreed with the statement. Only one question—“I was treated with respect”—received three “strongly disagree” answers. Two of the individuals who strongly disagreed with this statement were those who had commented about being dropped from the program by letter and had never received services.

In addition to the participants who rated TBI Project services negatively in the survey's closed ended questions, a few other respondents gave comments that expressed dissatisfaction with some aspect of services. One individual felt that he had not received adequate support when he moved out of the area, and would have like to have had information about TBI services available in his new city of residence. Three others were offended that they had not been notified that their service coordinator was leaving the program, and they only found out after the fact.

Finally, a few respondents offered suggestions about how services could be improved or made more accessible. One individual suggested that the TBI Project offer a "refresher course" for participants who had been involved with the program for a number of years. Another respondent would like to have some support meetings scheduled during the day, since she was not comfortable driving at night and leaving her children at home.

Variation in Responses Across Sites

Participants of the four original sites (shown in gray in Figure 6.5, below) tended to be more positive about several aspects of service provision than did individuals served by the newer sites. This pattern emerged most strongly when participants responded to the statements about receiving needed information, receiving information clearly, dealing more effectively with daily problems,

Figure 6.5 Participant Satisfaction by TBI Project Sites: * Proportion of Participants Who Agree With Statement (n = 160)							
Survey Question	Clooney (n = 14)	CCCIL (n = 15)	CCNBC (n = 15)	Headway (n = 22)	Mercy (n = 18)	St. Jude (n = 50)	Pomeroy (n = 24)
Treated with respect	100%	94%	100%	91%	94%	96%	96%
Received information and assistance	100%	85%	93%	82%	89%	90%	82%
Information clear and understandable	100%	93%	93%	87%	100%	96%	92%
Services matched my goals	100%	73%	80%	92%	89%	84%	87%
Services helped with daily problems	85%	80%	87%	63%	89%	84%	70%
Better able to control my life	78%	60%	74%	68%	89%	87%	74%
Willing to use services again	100%	100%	80%	86%	89%	94%	92%
Would recommend to others	100%	94%	94%	87%	95%	98%	92%
Rating overall service (excellent or good)	100%	87%	94%	82%	89%	92%	79%

* Sites highlighted in gray were the four originally funded in 1990. The others were funded after 2000.

being able to control one's life, and using services again. In fact, Clooney's participants all agreed or strongly agreed with seven out of nine of the statements included in the survey. A number of reasons could explain the difference between the original and newer sites on these participant satisfaction measures, including the fact that the original sites have more overall experience in operating the project and their participants tend to have longer tenure in the program.

Nonetheless, participants appear to value particular strengths of each of the newer sites as well. Almost all (92%) Making Headway participants agreed that the site developed service plans with their individual goals in mind, while all CCNBC participants agreed that site staff treated them with respect and a large majority (87%) believed that program services improved their ability to deal effectively with daily problems. Most Pomeroy participants also agreed (87%) that services were planned around their personal goals, and 92% would recommend the program to other TBI survivors.

As noted above, fewer participants across all the sites agreed with the statements, "I am better able to control my life since participating in the program," and "I deal more effectively with daily problem as a result of program the services" than with other statements. Nonetheless, more Mercy participants agreed with both of these statements than did individuals served by the other sites. These results might be expected, given how soon many Mercy participants enter the program after injury or after release from inpatient rehabilitation.

None of the respondents from Clooney and CCNBC gave their sites negative ratings on their services. Of the other sites, CCCIL received negative ratings from only one participant, St. Jude from only two participants, Mercy and Pomeroy from three respondents, and Headway from six participants.

Overall, TBI Project participants were extremely positive about the program and appreciated the services they received. As a participant wrote on his survey, "Thank you for having these services. Nobody plans on being a TBI survivor or it happening to them until it happens, and then you need all the help you can get."

Interviews with Participants and Family Members

Evaluation staff interviewed a total of 28 participants and 14 caregivers during visits to the TBI Project sites conducted between January and April 2004. For the most part, we conducted these as individual interviews, although a few were done using a focus group format. We asked both participants and caregivers about program services they had used, their satisfaction with those services, any unmet needs, and suggestions for program improvement.

As a group, participants were extremely pleased with the services they received and appreciated the assistance and care they received from the staff on site. The most frequent compliments revolved around the uniqueness of the services available for TBI survivors. Many participants remarked that the individualized services offered by the sites were not readily available elsewhere. The rest of this section discusses comments offered during the interviews, starting with project services identified as most valuable to participants and their families, and then describing unmet needs, feedback on site staff, and potential improvements to the program.

Most Valuable Services

Participants mentioned a range of services that they considered to be the most valuable help they had received. Chief among these was help in developing their organization skills, such as time management and scheduling, dealing with mail, and managing finances. The degree to which participants valued this help is reflected in the ways that they referred to the project, such as “my organizing partner,” and “my backbone.” Assistance with goal setting, and “figuring out what I want to do,” was another service related to organizational skills that participants also valued.

Both participants and their family members also highly valued the provision of information about resources available in their local areas. Participants mentioned several important services that the Project sites had helped them access, including anger management counseling and groups, legal assistance, and neuropsychologists. One family member noted that the service coordinator continually checked on eligibility for services that the participant needed, looked for resources, and identified their costs. A participant noted, “There is no way for us to connect without [the program], both socially and resources. If they don’t know about a service they find it.”

“I really appreciate the support groups and the art therapy project. The support group helps a lot with normalization and socialization and gets me out of the house. I feel less depressed and look forward to spending time with my peers and learning from them.”

Advocacy was another service mentioned by many of the participants that we interviewed. Participants told of how project staff had accompanied them to meetings with DR counselors, the local housing authority, and doctors who didn’t understand TBI. One participant noted that his service coordinator had helped him in dealing with a traffic accident and with his credit card debt. A family member stated that site staff had advocated with the participant’s employer for ten months to keep the participant employed. Another participant appreciated the fact that site staff “stood up for me when I couldn’t do it myself.”

Help with the SSI/SSDI application and appeals process was yet another TBI Project service that many participants valued. During the interviews, respondents reported that site staff provided benefits counseling, advocacy within the application process, and referrals to attorneys specializing in Social Security issues. Participants also mentioned that assistance with applying for MediCal was another important service that sites provided. One participant said of site staff, “I call them first before I talk to MediCal, Social Security, or my social worker about any financial situations.”

Other services that participants appreciated included peer support groups, help in applying for college and other educational programs, assistance in locating volunteer jobs and with job search strategies and activities, help with financial management, and assistance in securing subsidized housing. In addition, several family members noted that the TBI education and counseling they had received from the TBI Project had been very valuable.

Unmet Needs

Despite the valued services that the TBI Project provided, participants and family members identified a number of unmet needs. The service gap mentioned most frequently was transportation. Lack of transportation was raised as an issue more often in the sites located in less metropolitan areas (e.g., CCNBC, Headway), but also came up during the interviews we conducted at Mercy and CCCIL, both located in cities that have public transit systems.

Both participants and family members expressed a need for family support groups, separate from support groups for survivors. One parent of a participant commented that she was “worried what will happen when I’m not around,” and hoped to get ideas and strategies from other families. A participant noted that he needed help for his family because they don’t understand what it means that he has a TBI even though he had given them TBI education materials. Another individual stated that his local site once had separate support groups for families and survivors, and that he missed having these services available.

A few participants mentioned the need for residential programs for people with TBI, and noted that supported living is not available in many areas of the state. Other unmet needs that participants identified included help with legal issues, social activities and help with social interaction, psychiatrists who understand TBI, more peer support groups, and regular hands-on help with organization and paperwork filing. One participant noted the need for more services to be available in general, especially those that focus on developing self-esteem.

Family members identified slightly different service needs than did the participants. Several family members were concerned about the lack of programs that could support their relatives with TBI in employment. One parent mentioned the need for respite care. This individual felt that she really could not take a vacation without someone to keep an eye on her daughter, to ensure that she took her medication. Another family member noted that although some of the services she and the participant needed were available in their local community, unfortunately, they could not afford them.

Feedback on TBI Project Staff

Interview comments about the project’s staff were overwhelmingly positive. Program staff impressed both participants and family members, with their helpfulness, accessibility, levels of knowledge, caring, and understanding of the challenges that TBI survivors face.

One participant noted that she had used all of the services offered at her site and was amazed that “everyone is still willing to help me.” Another appreciated the helpful staff on site and their “infectiously positive attitudes.” He also remarked that working with the staff formed a “great team” focused on his goals. A Southern California participant remarked that a particular staff person “goes out of her way to help. She goes beyond what anyone else would do.” A fourth participant said of staff, “They grease the wheels.”

Participants valued the fact that site staff members were accessible and flexible. As one individual remarked of her service coordinator, “She’s always accessible, and I can talk to her the same afternoon.”

A family member observed that site staff were knowledgeable and “presented everything well.” Both participants and family members appreciated that staff were professional and “know what they’re doing.”

TBI Project participants also valued the fact that staff are caring, and that the program “feels like a family.” One participant said, “They treat us like normal people, with respect, and nurture us when necessary. People with TBI feel like human beings here.” Another stated, “These are good people.”

Perhaps the most valued trait of site staff is their understanding of living with a TBI. One participant called the program, “a place where they understand,” while another stated, “I would be dead if not for [the program]. So few people understand.” The caregiver of a participant remarked about site staff, “It’s nice not to be fighting the battle by yourself.”

Suggestions for Improvement

When asked if he had any suggestions for improving the TBI Project, one participant began his answer with, “These are not criticisms, but add-ons.” The responses that other participants gave to the same question support his statement; in general, they would all like to see the program expanded. Several were concerned that the project be made accessible to more people. One participant urged, “This program is critical. It has to be duplicated in many places and expanded.”

Quite a few participants and family members felt that further increasing public awareness about TBI is still greatly needed. As one family member noted, “The level of ignorance about head injury is amazing.” Interview respondents suggested various strategies to meet this goal, including publicity about the sites and public service announcements on TBI. One participant recommended that TBI education begin in elementary school, focused toward teachers, students, and the PTA. This individual also pushed for better TBI education of law enforcement and probation officers. Another suggested that doctors, other medical service providers, and those in the legal profession be taught to recognize the impact that a TBI can have on a person’s life. Participants also suggested that the TBI Project increase its outreach. One parent of a TBI survivor asked, “How come I didn’t know about [the program]”?

Other participants were focused on improving the services they currently were receiving. Several participants recommended that the sites have more staff, including one who said she sometimes had trouble contacting project staff because they were out of the office or busy helping someone else. Another participant proposed that services be expanded to include a peer advocate program, more social events, and more peer support groups. This individual would also like to see a resource guide or phone directory developed for people with TBI.

Both participants and their families recognized that changes such as those proposed above would need increased funding. In response to the interviewer’s question about suggested program improvements, one participant answered simply, “Give them more money.”

7. Community Impact

While previous chapters have focused on services to and outcomes for individuals with TBI, this chapter focuses on broader community outcomes. In addition to coordinating and providing services to TBI survivors, the TBI Project aims to:

- Provide families, caregivers, and professionals with information, advice and referral services, caregiver support, and family and community education;
- Provide outreach activities to meet the cultural and ethnic needs of the population with TBI in the geographic area served;
- Work closely and coordinate with organizations serving persons with TBI to ensure that the greatest numbers of organizations participate; and
- Assist in identifying and documenting service needs and in developing necessary programs and services to meet the needs of adults with TBI in the geographic area served.

The evaluation used two major sources of information to assess the efficacy of the TBI Project sites in providing information, referrals, training, and education to participants, family members, health and social service professionals, law enforcement professionals, and others in the community. First, we analyzed data from the quarterly site statistics for FY03-04, including both the number and types of individuals who attended community services and the staff time allocated to these activities. Second, during visits to each site, we collected information about the sites' community outreach activities, training workshops and seminars, participant and family support groups, and development of community networks aimed at improving services available for individuals with TBI.

This chapter first describes information and referrals provided to the community at large, including a summary of the TBI Project Hotline activities. We then discuss each of the types of community outreach and education efforts, as well as data reported by the sites about the time committed to each of these activities. It should be noted that the time reported for various activities included time that staff spent arranging, coordinating, preparing for, and conducting various community services, as well as time devoted to participant documentation, follow-up, and travel. Finally we describe some of the key community linkages that sites have developed to strengthen their services to participants.

Information and Referral

All of the TBI Project sites provide basic information and advice about brain disorders to the general public. The sites are intended to serve as a single “point of entry” to information as well as referrals to TBI service programs or other community resources. Figure 7.1 reports site activity in responding to inquiries and providing information and referral (I&R) services to potential participants, family members and caregivers, professionals, and other types of inquirers. An “inquiry” is included in this category when no intake form is completed. The numbers

represent an unduplicated count of participants, families or caregivers, and agencies that contacted each site. As the Figure shows, collectively the sites responded to almost 6,900 inquiries, provided almost 7,500 referrals in response to those inquiries, and devoted over 3,000 hours to providing I&R services.

Figure 7.1 Inquiries, Information and Referral								
Measure	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Inquiries From Potential Participants	1242	902	171	4	26	34	75	30
Referrals Provided to Potential Participants	1418	902	186	1	14	54	205	56
Inquiries From Family Members/Caregivers	2540	2312	27	10	27	53	55	56
Referrals Provided to Family Members/Caregivers	2742	2312	41	0	16	105	120	148
Inquiries From Professionals and Agencies	2993	2480	49	18	46	101	226	73
Referrals Provided to Professionals and Agencies	3124	2480	57	2	26	156	269	134
Inquiries From Others	113	0	11	0	3	0	97	2
Referrals Provided to Others	179	0	15	0	2	0	159	3
Total Number Of Inquirers	6888	5694	258	32	102	188	453	161
Total Number Of Referrals Provided	7463	5694	299	3	58	315	753	341
Total Hours Of Service	3345.5	2688.3	158.3	12.3	44.5	115.5	225.0	101.8

The figure also illustrates the enormous variation across sites, which appears to correspond to the density of the geographic area served by each site. For example, across the sites the two Southern California sites provided the most I&R services. Clooney responded to 5,694 inquiries over the course of FY03-04, and providing at least one referral for each inquiry, while St. Jude responded to 491 inquiries. Mercy and Pomeroy, both serving slightly less populous areas than the Southern California sites, provided I&R services to similar numbers of inquirers. Of these two sites, Mercy answered more calls and Pomeroy provided more referrals. The newest sites (CCNBC and Headway) reported the fewest inquiries, which is understandable given that they were still newly establishing their reputations in the community as a place to call for information and referral for TBI services and issues. Further, CCNBC and Headway are located in the least dense

communities of all of the site's communities, which means that compared to other sites, they have the smallest number of potential callers in their service areas.

Another type of variation across the sites is in the ratio between the number of reported inquiries and the number of reported referrals in response to those inquiries. For example, St. Jude reported more referrals than inquiries across all types of inquirers, indicating that they provide and record multiple referrals for many of their calls. Headway reported fewer referrals than inquiries, perhaps reflecting the fact that this site is located in a rural area, where resources for people with TBI and other disabilities are relatively scarce. Thus, not all inquiries to Headway result in a referral. Clooney reported identical numbers for both inquiries and referrals, suggesting that they typically provide some kind of referral, whether to services or information, in response to all their calls.¹

Inquiries came most frequently from professionals and community agencies across all of the sites except CCCIL, which reported most of its inquiries coming from potential program participants. Given that CCCIL is widely known as a consumer-driven organization, this difference is not surprising. Family members/caregivers were the second most frequent source of inquiries across all of the sites.

One of the challenges of providing information and referral sources is ensuring that the information provided is accurate and current. St. Jude sends out an annual request for information to all of the local organizations it uses as resources to ensure that the site's referral information is current. The other original sites use similar mechanisms to guarantee that they are disseminating accurate information.

Toll-Free Hotline

In addition to the I&R services routinely provided by all of the sites, the Betty Clooney Foundation receives additional funding to operate the TBI Project's Toll-Free Hotline. This toll-free information line is staffed during regular business hours, and serves both California and the nation at large.

Figure 7.2 provides a summary of call activity for the hotline during FY03-04. As the Figure shows, the hotline responded to 6,457 calls during the year. The shortest calls were three minutes long and the longest ranged from 55-120 minutes. The activity was heaviest during the first quarter and dropped off somewhat during subsequent quarters.

Almost two-thirds of the calls were from care providers, another 28% were from professionals and about 7% were from TBI survivors. While the vast majority of calls were from Southern California (82%) where Clooney is located, almost 200 were from Northern California and almost 1,000 were from outside of California.

¹ Because of the volume of calls that the site receives, Clooney staff generally do not track the number of referrals that they provide to each inquirer, but provide at least one referral to each caller.

Figure 7.2 TBI Project Toll-Free Hotline Report Fiscal Year 2003-2004						
Measure	1st Qtr	2 nd Qtr	3rd Qtr	4th Qtr	Total	
					N	%
Total Calls	2846	1752	1021	838	6457	100%
• Professional	798	438	335	243	1814	28%
• TBI Survivor	199	140	89	42	470	7%
• Care Provider	1849	1174	597	553	4173	65%
Source of Calls						
• Southern California	2305	1542	767	688	5302	82%
• Northern California	143	18	22	8	191	3%
• Outside California	398	192	232	142	964	15%
Average Length of Calls (in minutes)						
• Shortest Call	3	3	3	3	3	
• Longest Call	55	120	90	120	96.25	

Community Services

The sites provide several different types of community services, including support groups, workshops or seminars for professionals, workshops or seminars for TBI survivors and their family members, presentations about project services, and other types of outreach activities. This section outlines the types of activities that site staff have undertaken, the level of effort involved for each category, and the extent to which the local communities use these services.

Support Groups

Support groups provide a setting for participants, peers, family members and/or caregivers to provide emotional support and/or education about TBI. Among the participants that evaluation staff interviewed, support groups were one of the most valued services that the project provides.

Several of the sites emphasize offering support groups because, as staff said, many participants have few opportunities for socialization. Making Headway offers two support groups that meet weekly. The groups choose names for themselves, and one of the groups calls itself “The Headbangers.”

CCCIL staff facilitate three support groups per month, each with a different focus. The social group meets at a local coffee house. A second group meets at the United Way office and focuses on “TBI survival skills” such as problem-solving, answering questions, and discussing issues specific to people with brain injury. The third group meets at a skilled nursing facility, and is targeted for SNF and group home residents.

A neuropsychologist facilitates the Pomeroy support group, which meets twice per month at the site's partner agency, a rehabilitation hospital. The service coordinators trade off in attending these groups, and find guest speakers when the regular facilitator is not available. One of the Pomeroy service coordinators spoke of using the support groups as a means of participant education. TBI survivors with recent injuries are often reluctant to admit they have a problem. Attending the groups sometimes helps these individuals accept that they have a disability and

Figure 7.3
Fiscal Year 2003-2004 Outreach and Community Services

Measure	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Support Groups	192	14	35	0	97	19	2	25
Number of Attendees*	1371	138	334	0	646	84	49	120
Average Number of Attendees per Group	7.1	9.9	9.5		6.7	4.4	24.5	4.8
Average Hours Spent Per Group	1.6	2.1	2.6		1.3	.4	6.8	1.7
Workshops/Seminars to Professionals	76	9	24	0	8	9	17	9
Number of Attendees*	2351	104	438	0	37	185	1233	354
Average Number of Attendees per Presentation	30.9	11.6	18.3	-	4.6	20.6	72.5	39.3
Average Hours Spent Per Workshop/Seminar	6.2	2.8	4.6	-	4.4	5.8	9.9	9.0
Workshops/Seminars for Participants and Families	74	22	18	0	1	7	24	2
Number of Attendees*	2298	263	594	0	13	136	1156	136
Average Number of Attendees per Presentation	31.1	12.0	33.0	-	13.0	19.4	48.2	68.0
Average Hours Spent per Workshop/Seminar	4.8	1.7	4.8	-	5.0	3.5	7.5	10.8
Outreach Presentations	136	12	24	3	11	12	36	38
Number of Attendees*	1752	208	615	106	50	90	552	131
Average Number of Attendees per Presentation	12.9	17.3	25.6	35.3	4.6	7.5	15.3	3.5
Average Hours Spent per Presentation	2.1	0.5	5.1	2.3	1.6	1.1	2.3	0.8
Newsletters, Marketing Materials	10241	7835	17	1104	650	0	76	559
Community Network Meetings	127	8	48	2	18	29	24	18

* Attendance at Community Service meetings and events is not tracked as an unduplicated count.

might need some help. Bringing in guest speakers provides an opportunity to provide information participants need but might not individually ask for.

Mercy's Bridges program includes a support group session as part of its curriculum. Other Bridges activities include physical fitness recreation and leisure, organization, cognitive development, and community reintegration activities. Clooney organizes support groups intermittently depending upon participant schedules and the availability of staff or interns to facilitate the group. The location of these groups varies.

CCNBC and St. Jude do not offer support groups themselves, but direct participants to groups available in their communities. At the time of the evaluation's site visit, however, some St. Jude participants were in the process of starting their own peer support group.

Figure 7.3, above, summarizes data on community services and outreach efforts reported by the sites on their quarterly reports to DMH. Across all sites, staff convened a total of 192 support group meetings during FY03-04. Headway had the greatest number of support group meetings with 97, while CCNBC had no support groups. On average across all sites, seven participants attended each support group. St. Jude had the greatest number of participants per support group with 25 on average, while Mercy had the fewest with four.

The average support group lasted less than two hours (1.6) across all sites. Support groups (and preparation time) at St. Jude lasted the longest with 6.8 hours, while Mercy support groups lasted under half an hour.

Seminars and Workshops

This category of community service includes workshops, presentations, and seminars designed to improve the understanding of the nature and consequences of TBI among participants and family members. It also includes presentations designed to improve the understanding of the nature and consequences of TBI at professional conferences as well as at training sessions for service providers, law enforcement personnel, and other professionals.

Site staff reported that their geographical service areas for community education and training might be different than that for participant services. For example, Headway provides participant services to Humboldt County only, but the site is committed to providing community education to Mendocino and Del Norte Counties as well. Similarly, Pomeroy serves participants who reside in San Francisco County, but also seeks to provide community education services in neighboring San Mateo County. CCNBC staff said that they had made few community education presentations to date, but that their service area for such services extends to Northern Santa Barbara County. Finally, CCCIL's community education service area includes Salinas.

The five sites hosted by relatively large organizations usually start community education of professionals with in-service training, seminars, and other presentations about TBI to staff in other departments of their own organizations. Mercy, for example, provides professional education on TBI to the Medical Center's staff in general, offering in-services for clinical staff,

and focusing on trauma unit staff in particular. St. Jude staff provide this training to hospital staff in collaboration with a neuropsychologist.

Staff from almost every site mentioned providing training to members of the local police department, parole officers, district attorney's office, and/or court personnel. CCCIL's seminar for the Capitola police department included a panel discussion with people with disabilities, including at least one TBI survivor. Mercy also has provided professional education to SSI staff and disability attorneys, while Pomeroy provided a TBI seminar for Protection and Advocacy staff who were about to start a grant focusing on services to TBI survivors. Site staff also reported providing these services to a rehabilitation hospital, homeless agencies, mental health providers, and One-Stop Career Centers.

The cooperative agreement between DMH and DR serves as a mechanism to support professional education of DR counselors. The interagency agreement covers reciprocal training between the TBI Project sites and DR to ensure successful collaboration between the organizations. While DR provides training to the sites to help project staff understand DR's mission, goals, policies, and procedures, the TBI Project sites provide training to DR staff to help them understand the specific needs of TBI survivors as they relate to vocational activities and outcomes. All of the sites that participated in the cooperative agreement found the reciprocal training helpful. In particular, DR staff who have worked with the sites have significantly increased their knowledge levels about TBI and its effects on survivors.

The sites also provide seminars and other presentations focused on participants and their families. CCCIL, for example, holds a quarterly "Life After BI" session with guest speakers addressing various topics of interest to individuals with TBI and their families. While these meetings are open to anyone, primarily TBI survivors and their families attend them.

Figure 7.3 shows that the sites provided 76 seminars and workshops to 2,351 professionals over the course of the year. These ranged in number from a total of eight seminars provided by Headway staff to 24 provided by CCCIL. On average, sites invested about six hours per workshop or seminar. Including preparation time, logistics, and travel, Clooney staff spent an average of under three hours per workshop, while St. Jude staff spent about ten hours per workshop. CCNBC did not report providing any workshops/seminars to professionals during the year.

The TBI Project sites also provided 74 workshops/seminars to 2,298 participants and their family members during the year, ranging from a low of one workshop by Headway to a high of 24 workshops by St. Jude. On average, sites invested almost five hours of staff time per workshop or seminar, ranging from a low of just under two hours at Clooney to nearly 11 hours per workshop at Pomeroy.

Outreach

Outreach is defined as services that describe and/or provide education about the TBI project site and its services. Outreach may include presentations to organizations, schools, and professional groups. Quarterly site statistical reports summarized in Figure 7.3 indicate that the sites provided

a total of 136 outreach presentations to over 1,700 attendees over the course of FY03-04. CCNBC reported making three presentations, while Pomeroy made 38 outreach presentations. The size of the presentation audiences varied substantially across sites. While audience size averaged about 13 attendees per presentation, the number varied from a low of about three attendees per presentation at Pomeroy to an average of about 35 attendees at CCNBC. As with other types of community services, the sites varied widely on the amount of staff time devoted to these presentations, ranging from half an hour per presentation at Clooney to just over five hours per presentation at CCCIL. Across the project as a whole, staff devoted two hours per outreach presentation.

As part of establishing their programs, the three newest project sites (Making Headway, Pomeroy, and CCNBC) spent significant amounts of time and effort in outreach activities. Pomeroy staff described taking care not only to inform other service providers in San Francisco about the project, but also to establish relationships with hospital social workers, independent living center staff, the Family Caregiver Alliance, and the Northern California Brain Injury service providers group. Headway staff discussed similar efforts, and they believe that the TBI Project has allowed the site to significantly increase its presence in the community.

Site staff have adopted a range of interesting strategies for outreach. The CCCIL project director writes regular columns for three local newspapers. Both of this site's service coordinators are TBI survivors. One of the services coordinators has collaborated with the local police department's Bike Patrol in making presentations at schools about the importance of wearing bicycle helmets and other protective equipment.

The St. Jude project director attends a support group twice a month at a nearby hospital as outreach to potential participants. She also visits cognitive retraining classes for TBI survivors once per month at Coastline Community College for the same reason. The primary St. Jude service coordinator is registered with an informal speakers' bureau through the local Volunteer Center, and has made several presentations on TBI as a result. Most notably, he spoke to a group of DUI (driving under the influence) offenders who were all under age 21.

Clooney's project director described participating in numerous committees in the past as a means of outreach to the community. He has withdrawn from most of these activities because of lack of resources. Staff at each of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) all reported reducing the amount of outreach and community education activities they have done in recent years because project funding is no longer sufficient to cover both services to participants and extensive community services.

The Welfare & Institutions Code mandates that the TBI Project sites provide outreach activities to meet the cultural and ethnic needs of the population with TBI in the geographic area served. From the interviews that the evaluation team conducted with site staff, it is not clear to what degree the sites have been able to meet this requirement. Only two of the projects had bilingual staff during the evaluation's study period.

Site staff face a daily choice between providing assistance to individuals with TBI who have already found the project and conducting outreach to recruit more participants (whom they may not have the resources to serve adequately). Given the amount of funding available to the sites, staff have chosen to focus on serving participants to the best of their ability.

In addition to conducting outreach presentations, all of the sites (with the exception of Mercy) also developed and distributed newsletters and marketing materials. They reported distributing a total of 10,241 materials (see Figure 7.3). Clooney reached the largest number of individuals with this approach, and distributed a total of 7,835 newsletters and marketing materials. CCNC also distributed well over a thousand of such materials.

Community Linkages

To work effectively, the TBI Project's coordinated services model requires that staff work closely with other service providers and organizations that support persons with TBI. The Welfare & Institutions Code assumes that the project sites will maintain a broad network of relationships with local providers of health, social, and vocational services to individuals with TBI and their families. The legislation further requires the sites to work cooperatively with these groups and providers to improve and develop needed services, and to promote a well-coordinated service system, taking a leadership role as necessary.

All of the sites have been actively engaged in developing linkages with other agencies in the community. As shown in Figure 7.3, above, the sites' quarterly reports to DMH include the number of community network meetings in which staff participate. Cumulatively, the sites participated in a total of 147 community network meetings throughout FY03-04. The sites participated in an average of 21 meetings each, ranging from a low of two network meetings attended by CCNBC staff to a high of 48 meetings by CCCIL staff.

Mercy serves as the lead agency for the Sacramento TBI Network, convening quarterly meetings of this group of 20 – 25 providers of services to individuals with TBI. The group is working to maximize its collective impact, facilitating referrals between the members of the group, building relationships, and providing public and professional TBI education. The Network has produced a resource guide for relevant services available in the area.

CCCIL serves a similar role for Santa Cruz County's community consortium of TBI service providers. The consortium serves as a venue for case conferencing, TBI education, updates on policy changes, and outreach presentations on services each agency offers. CCCIL staff described their role in the consortium, and as service providers, as being "the spider in the web connecting to existing community services."

St. Jude is part of the Anaheim Human Services Network and Clooney is a member of the Carson Community Council. The St. Jude project director also serves on the boards of directors of several other agencies, including those providing housing assistance to people with disabilities.

In addition to community network meetings, MOUs and cooperative agreements serve as another measure of the degree of coordination that sites have achieved with other service providers in

their communities. Making Headway has the largest number of formal collaboration agreements of all of the TBI Project sites: interagency cooperative agreements with four local agencies and a vendor contract with another. This site has signed cooperative agreements with:

- Eureka Adult School (for TBI classes);
- Redwood Caregiver Alliance (for operating a TBI caregiver support group);
- St. Joseph Hospital (for a TBI support group and TBI class); and
- Senior Resource Center (for Linkages case management, space for support groups, and referrals).

Headway is also a vendor for the local Regional Center, and staff work closely with the County's Department of Mental Health in serving individuals with dual TBI/MI diagnoses.

The CCNBC site's host organization, OPTIONS, has a number of interagency cooperative agreements with agencies in San Luis Obispo County. While these agreements support the provision of services for project participants, they were not forged with the TBI Project specifically in mind. The site does have an MOU with Coast Caregivers Resource Center for outreach and caregiver education. CCNBC staff have also developed close working relationships with DR staff, which will be a strong support for the site in working under the DMH/DR interagency cooperative agreement.

St. Jude holds an MOU with the Orange County Volunteer Center to help develop volunteer placements for participant community reintegration services. This site also contracts with the Orange Caregiver Resource Center to provide support to families of participants.

Pomeroy is included under the DMH/DR cooperative agreement, which provides a structure that facilitates the site's collaboration with DR counselors. Site staff meet every other week to discuss their mutual clients. The two agencies also hold a quarterly meeting to discuss administrative matters. One of the results of the administrative meetings was a written protocol for interagency referrals between the two organizations.

TBI Project staff from at least two sites described challenges to interagency collaboration that they have encountered. CCCIL staff have encountered increasing resistance to scheduling consortium meetings as consortium member agencies experience increasing funding cuts. Such funding reductions have two important consequences: 1) resulting turnover within an agency may mean that the agency—and the consortium—loses the staff person who had “the passion” for working with TBI survivors; and 2) remaining staff are overworked, making it harder than ever to bring people together for case coordination or consortium meetings.

Staff from St. Jude mentioned that implementation of the patient confidentiality provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) has created challenges to collaboration with DR and other agencies because of the law's limits on data sharing. While these requirements may be addressed by using specific release forms, completion of such forms can be a barrier for some participants.

8. Summary of Key Findings and Recommendations For Program Improvements and Future Evaluation Efforts

This chapter is divided into three sections. First, we summarize the key findings presented in the previous chapters. Next, we discuss recommendations for program improvements based on our observations of TBI Project implementation. Finally, the chapter ends with recommendations for improving the data systems that the sites use to document their services and outcomes.

Summary of Key Findings

Participants Served

As a group, the TBI Project sites served a total of 610 participants in FY03-04. The evaluation examined data on a subset of these participants, a sample of 213 individuals who first enrolled in the program between February 1, 2003 and June 30, 2004. The “typical” TBI Project participant included in the evaluation’s study sample is a 41-year old single white male who has attended some college, receives SSI or SSDI, and lives either alone or with a family member.

Over half of participants were injured in a motor vehicle accident, and 28% of participants’ traumatic brain injuries were related to use of drugs or alcohol, either by the TBI survivor or another individual. One-quarter of participants had experienced their TBI in the year prior to enrolling in the TBI Project, though the average length of time since injury at intake was ten years.

Three-quarters of all participants were hospitalized as a result of their traumatic brain injuries. While the average hospital stay was about three and a half months, half were in the hospital for less than two months. Half of all participants experienced a coma after sustaining their TBI. Participants’ comas ranged in duration from about an hour to ten months, with an average of just over one month of unconsciousness. Over a third of all participants experienced amnesia after their traumatic brain injuries, with participants experiencing the condition for an average of two and a half months.

Overall, just over one-third of program participants had a history of substance abuse prior to entering the program. Of these, 87% were no longer drinking or using drugs at intake, and on average, they had been clean for five years at enrollment. However, 18% of participants were identified as—or suspected of—having a problem with drug or alcohol abuse at the time they enrolled in the program.

TBI Project staff assessed participants’ presenting needs at intake, using a list of 26 types of services. Participants in the study sample reported needing an average of 4.5 services. The most frequently needed services were counseling, self-help/support groups, and vocational rehabilitation.

Only 11% of participants were working at the time they entered the TBI Project, and another 22% were DR clients. Nonetheless, a full two-thirds of participants expressed a desire to work at the time they enrolled in the program, with 29% desiring not to work.

Services Provided

The evaluation used two sources of information about service provision among the TBI Project sites: 1) aggregate data from the project's quarterly reporting system on the number of participants served, units of service provided by type of service, and number of inquiries during FY03-04; and 2) information collected on the project's six- and 12-month assessment forms about the services used by the 125 individuals in our study sample for whom six-month data were available.

Staff from the seven sites conducted a total of 363 intakes during FY03-04. Staff at the four original sites (Clooney, CCCIL, Mercy, and St. Jude) were more likely to complete an intake form for anyone with a brain injury who called the site, while staff at the newer programs tended to collect intake data only for those individuals most likely to enroll in services.

TBI Project staff conducted 202 initial assessments during the last fiscal year. The sites completed 106 six-month assessments, 90 12-month follow-ups, and 71 18-month follow-up assessments during FY03-04.

Site staff developed 369 initial ISPs during the year. Pomeroy used a different approach to service planning than did the other sites, writing a new ISP for each new task, and wrote two-thirds of the new ISPs developed during the year. Overall, Pomeroy staff wrote an average of seven ISPs per new participant compared to one ISP per new participant at the rest of the sites. This pattern continued for updated ISPs, with Pomeroy staff writing significantly more service plans than staff at the other sites.

Among the smaller evaluation study sample, virtually all participants received case coordination services during their first six months in the TBI Project. As a group, participants most frequently used day program and social/recreational services after case coordination. Aside from case coordination, participants enrolled in one of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) tended to use more day program and social/recreation services than the others, and CCNBC and Pomeroy participants were more likely to use employment services than they were to take part in a day program or social/recreation services. Overall, across all the sites participants used an average of two types of services during their first six months in the program.

Nearly all of the 54 individuals for whom 12-month data were available continued to use case coordination services between six and 12 months after enrollment. The proportion of participants using each type of service remained fairly constant from six to 12 months. Participants used a slightly larger number of services during their second six months in the program than they did in the first—an average of three different types of services during their second six months compared to two different types during their first six months.

For the 125 participants for whom both intake and six-month assessments are available, the proportion of participants who needed each type of service decreased between intake and the six-month assessment. Further, for services that specifically addressed needs listed in the form, the majority of participants who were identified as needing a service at intake had received the corresponding service by their six-month follow-up.

Participant Outcomes

The evaluation's primary measure for assessing the degree to which TBI Project services help to improve participants' reintegration into their communities is the Community Integration Questionnaire (CIQ). This instrument was specifically designed to measure community integration among survivors of TBI. Because this analysis requires that data for both intake and six-month observations be available, the sample size for these results was 125 participants.

Across all the sites, just over half of the outcome sample had an increase in their overall CIQ scores in their first six months of program participation, and their average total CIQ scores increased by 79% between intake and six months. Similarly, two-thirds of the 51 individuals in the 12-month outcome group experienced an increase in total CIQ score by one year post-enrollment and, on average, their scores increased by 74% during this period. Participants who experienced a positive change tended to be individuals who had relatively low CIQ scores at intake and therefore those who could most benefit from project services.

In addition to the CIQ, we examined various changes in day and vocational program participation, education and employment status, income source, and living situation. We classified changes as being either positive (e.g., entered employment, moved out of a skilled nursing facility, secured more stable source of income) or negative (moving into a dependent situation with family members; decreasing participation in or leaving day program without entering employment). Almost three-quarters of participants for whom data were available at six months had at least one positive outcome, while only 20% experienced at least one negative outcome. Further, the majority of participants at each of the sites experienced at least one positive outcome.

Customer Satisfaction

The evaluation used two methods of measuring customer satisfaction among TBI Project participants: 1) a mail survey of participants; and 2) interviews with both participants and their family members completed during visits to each of the sites.

Over three-quarters of the 160 participants who completed the mail survey agreed with each positive statement on the questionnaire, and at least half "strongly agreed" with each statement. Only 15 respondents replied negatively to any one of the survey questions.

Participants of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) tended to respond more positively to survey statements than did participants from the newer sites about receiving needed information, receiving information clearly, dealing more effectively with daily problems, being able to control one's life, and using services again. On the other hand, participants served

by the newer sites (Headway and Pomeroy) tended to be slightly more positive about their site's ability to develop service plans with their individual goals in mind, and CCNBC participants were more likely than those served by most of the other sites to believe that program services improved their ability to deal effectively with daily problems.

Overall, TBI Project participants were extremely positive about the program and appreciated the services they received. As one participant wrote on his survey, "Thank you for having these services. Nobody plans on being a TBI survivor or it happening to them until it happens, and then you need all the help you can get."

The feedback from participants and their families collected during site visit interviews were similarly glowing. The participants interviewed were extremely pleased with the services they received and appreciated the assistance and care they received from the staff on site. The most frequent compliments revolved around the uniqueness of the services available for TBI survivors. Many participants remarked that the individualized services offered by the sites were not readily available elsewhere.

Community Outcomes

The TBI Project sites provide several different types of community services, including support groups, workshops or seminars for professionals, workshops or seminars for TBI survivors and their family members, presentations about project services, and other types of outreach activities. Collectively, the sites responded to inquiries from almost 6,900 individuals, and provided over 7,400 referrals in response to those inquiries. Staff of the seven sites convened a total of 192 support group meetings during FY03-04. On average across all sites, seven participants attended each support group, which lasted just under two hours.

The TBI Project sites provided 76 seminars and workshops to 2,351 professionals over the course of the year. Including preparation time, logistics, travel, and presentation, staff invested about six hours per workshop or seminar. Site staff also provided 74 workshops/seminars to almost 2,300 participants and their family members during the year. Staff spent less time on participant/family workshops than they did on professional workshops, an average of five hours of staff time per workshop or seminar.

Over the course of FY03-04, the seven sites provided a total of 136 outreach presentations to 1,752 attendees. The sites also developed and distributed 10,241 copies of TBI Project newsletters and marketing materials during the year. Staff at the four original sites, in particular, noted that their outreach efforts had dropped considerably in the last year. Well-established in their communities after 14 years of operation, the reason these sites gave for the decrease in outreach effort was the decrease in funding available to support project activities. Instead, given the amount of funding available to the sites, staff have chosen to focus on serving participants to the best of their ability.

Cumulatively, the sites participated in a total of 147 community network meetings throughout FY03-04, for an average of 21 meetings per site. TBI Project staff described challenges to interagency collaboration that they encountered, such as increased resistance to scheduling

consortium meetings as consortium member agencies experience funding cuts. Such funding reductions have two important consequences: 1) resulting turnover within organizations may mean that the agency—and consortium—loses the staff person who had “the passion” for working with TBI survivors; and 2) remaining staff are overworked, thus making it harder than ever to bring people together for case coordination or consortium meetings.

Staff from St. Jude mentioned that implementation of the patient confidentiality provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) has created challenges to collaboration with DR and other agencies because of the law’s limits on data sharing. While these requirements may be addressed by using specific release forms, completion of such forms can be a barrier for some participants.

Recommendations for Program Improvements

The TBI Project has been designed to achieve six specific goals as specified in the authorizing legislation. The findings summarized above suggest that the project has been successful in providing and brokering services to persons with TBI within their communities and within the constraints of their current resources. Our overarching recommendation is to expand the funding for the project to enable it to reach many more persons with TBI throughout the state. At the same time, specific program improvements can be made to help the project more fully achieve the six goals.

1. Achieve comprehensive, coordinated public policy to design a coordinated services delivery system for adults with TBI. Coordinated public policy is difficult to achieve at the local level and may require additional state-level leadership. A coordinated services delivery system requires the engagement of a wide range of service agencies and programs in mental health, health care, education, vocational rehabilitation, workforce development, independent living, law enforcement, legal services, etc. State-level MOUs and cooperative agreements alone are not sufficient to ensure that coordination happens at a local level; state-level commitment, communication, and leadership can be valuable supports to local coordination efforts.

Recommendations: Build specific service design considerations into state-level cooperative agreements or MOUs, such as specifying that the Department of Rehabilitation provide DR services through specialist counselors. Build TBI training in as one of the contributions made by the TBI Project and make sure that every site has identified experts at their organization or through a community partner that can provide training to staff of collaborating agencies. Be sure that MOUs and cooperative agreements address mechanisms for state agencies to communicate with local agencies and hold local staff accountable for making good faith efforts to implement the agreements.

2. Ensure the existence of an array of appropriate programs and services for adults with TBI and their families. Ensuring a full array of services requires both an understanding of the spectrum of services that persons with TBI might need, and a full assessment of the resources available in the community that are able to address the various needs of TBI survivors. Most sites have identified a combination of services that they are well-suited to offer, as well as a selection of community agencies with whom they can collaborate to fill some of the most obvious gaps.

Each site is very idiosyncratic in its approach, however, and the sites vary hugely in the extent to which various types of services are available in one community versus another.

Recommendations: Consider moving toward more of a “systems approach” to service delivery that identifies the spectrum of services that should be in place to meet the needs of persons with TBI, and uses a systematic community needs assessment process to identify resources and gaps. Use ongoing program evaluation to identify promising and transferable practices. To ensure the most effective use of these lessons, provide technical assistance and support mentorship and sharing of information and resources among sites.

3. Place a high priority on utilizing community resources in creating opportunities for persons with TBI to live in the community and achieve their maximum potential, and for families to maintain a brain injured adult at home when possible or in other community-based alternatives when necessary. Project sites seem to have been successful in utilizing community resources and serving in a case management and service coordination role for their clients.

Recommendations: Have sites that have been successful in forging relationships with different types of community organizations coach other sites in strategies for developing relationships with counterparts in their communities.

4. Assist persons with TBI to attain productive, independent lives, which may include paid employment. Currently, sites place some but not a concentrated focus on helping clients develop and continue to improve a full range of compensatory skills, typically because they assume this is something that has been addressed through prior rehabilitation services. Assisting individuals with TBI to become more productive and independent often involves ongoing work on acknowledging and coping with TBI-related limitations, especially since these may change over time or in response to different settings and circumstances as clients move toward community reintegration or employment. In addition, site staff may not be expert at identifying substance abuse issues or assessing vocational readiness.

Recommendations: Include independent living skills training and individualized assistance in developing and improving compensatory skills within the core services provided by the project, or require that they be addressed directly through collaboration with community partners. Identify a common prevocational/vocational assessment tool to identify work readiness skills and needs, and train staff in how to administer it. Provide site staff with training on using the Michigan Alcoholism Screening Test (MAST), Drug Abuse Screening Test (DAST), or other standardized tools to identify participants who have potential substance abuse problems.

5. Participate in a statewide uniform database for the TBI program in order to measure the effectiveness of the TBI sites and a coordinated service approach, as well as monitor the progress of the statewide implementation of Chapter 1023, Statutes of 1999 (AB 1492). The project has made considerable progress in implementing uniform data collection through the use of the common assessment form, the CIQ, and a common customer satisfaction survey. Nonetheless, a number of improvements could be implemented, including those described in a later section of this chapter. In addition to improvements in uniform data collection, however, another important aspect of implementing common measures is to establish a routine for using the data to monitor progress and inform program improvement on a regular basis.

Recommendations: Use technology to generate routine reports that provide monitoring information across the project as a whole as well as for each site; and provide timely feedback on performance to the sites. Use performance information to identify areas of technical assistance needed by the sites and to inform funding decisions. Use the contracting process to require explicit program improvements by specifying required program components and having sites specify how they will address these requirements in their funding proposals. Re-compete the contracts periodically to encourage continuous program improvement.

6. Serve a population that is broadly representative with regard to race and ethnicity of the population with traumatic brain injury in the geographical service area. Under the current level of funding, outreach is not a high priority for most sites, with most of their resources being devoted to client services instead. In order for sites to serve a more representative population, staff need to develop community linkages with ethnic/multicultural organizations, hire bilingual staff, and target outreach to specific language and cultural communities. In addition, they may need to target education about long-term TBI service needs to the medical providers and organizations that serve ethnic and language minorities in their community.

Recommendations: Consider a higher funding level for sites in areas with large underserved communities. Require sites to specify in their funding proposals the community linkages, targeted outreach approaches, and other strategies they will use to ensure the population they serve is increasingly representative of the racial and ethnic diversity within their target service area. Consider providing training to site staff in strategies and resources for accommodating clients with limited English proficiency.

Recommendations for Data Collection and Evaluation

In the process of analyzing information that the TBI Project sites collect and report, the evaluation team examined in depth the policies and processes that the project uses to document its operations and outcomes. The following recommendations are based on our investigation of these systems, and are organized around the requirements for the evaluation included in California Welfare and Institutions Code Section 4353-4359.

1. The department, with the advice and assistance of the working group, shall develop an independent evaluation and assist sites in collecting uniform data on all clients.

The sites have made a major step forward in developing common intake and assessment forms that now are being used across the TBI Project. Unfortunately, other than assisting to develop a common customer satisfaction survey, further refining the set of data that the sites collect was beyond the resources available to the evaluation team. The existing data collection forms, along with the quarterly reporting system for site statistics, still fall short of effectively documenting the project's services and outcomes in some areas. Limited instructions exist to ensure common definitions of the data items across sites, thus site staff have adopted inconsistent definitions that weaken the validity and usefulness of the data they do collect. Further, DMH lacks the resources to adequately analyze information generated by the existing quarterly reports in order to use it effectively for ongoing monitoring, feedback, and oversight of project services.

Recommendations: Assuming the Legislature continues to invest in the TBI Project to provide much needed services to TBI survivors, it will also need to invest more funds to improve data systems to document both the services provided by the sites and the outcomes of participants who use project services. The improvements needed cross several dimensions and include the following recommendations:

- Require all sites to maintain assessment data in a consistent electronic format that can be electronically transmitted and compiled centrally across all sites;
- Establish common definitions for all of the data items that sites collect, including documentation of why they are collected and for whom they should be collected;
- Provide training to staff at every site to ensure that they understand both the definitions and data collection methods;
- Ensure that unduplicated counts of participants are available in the quarterly reporting system for all services included in that system;
- Refine both the assessment data set and the quarterly site statistics to include outcome measures, including reason for termination from the project; and
- Provide the sites with training on how to use the data they are collecting for their own management and internal evaluation purposes.

2. The evaluation shall test the efficacy, individually and in the aggregate, of the existing and new project sites in the following areas:

(A) The degree of community reintegration achieved by clients, including their increased ability to independently carry out activities of daily living, increased participation in community life, and improved living arrangements.

The CIQ appears to be a useful instrument for measuring community reintegration and participation in community life, and site staff have succeeded in implementing use of this assessment tool on a regular basis. However, it does not directly address participants' ability to carry out activities of daily living. For the most part, individuals served by the TBI Project are independent in Activities of Daily Living,¹ but many have limitations in Instrumental Activities of Daily Living (IADLs).² The CIQ captures some—but not all—of the IADLs. The TBI Project's current assessment data set includes a detailed question about living arrangements; however, as we discussed in Chapter 5, some of the changes in living status are ambiguous, and dependent upon knowledge of an individual participant's situation. Given the timing of

¹ These are eating, bathing, dressing, toileting, and transferring. See: Joshua M. Wiener, Raymond J. Hanley, Robert Clark and Joan F. Van Nostrand. "Measuring the Activities of Daily Living: Comparisons Across National Surveys, Executive Summary," in *Journal of Gerontology: SOCIAL SCIENCES* (November 1990, Volume 45, Number 6, pp. 229-237). <http://aspe.hhs.gov/daltcp/reports/meacmpes.htm>

² These are light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. Lawton, M.P. and E.M. Brody. "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living," *The Gerontologist*, 9: 179-186, 1969. See: http://research.aarp.org/health/ib32_disability.html

implementing a common data collection system and the length of evaluation, the observation period was too short to document these kinds of outcomes for many of the participants.

Recommendation: Change the evaluation and TBI Project data collection requirements to include IADLs and/or other measures of participant functional abilities. Consider whether changes in ability to drive should also be collected. Revise the assessment form to capture whether changes in income and living situation at follow-up were positive or negative. These changes would allow the site manager, program monitor, and or evaluator to assess the impact of TBI Project services on these particular outcomes. In addition, the evaluation should be continued over a longer time period to continue to document outcomes over a longer observation period.

(B) The improvements in clients' prevocational and vocational abilities, educational attainment, and paid and volunteer job placements.

The current TBI Project assessment form includes a single data item to capture changes in prevocational and vocational abilities, namely a question about the participant's employability. The form does not collect information about attending college, and educational attainment is assessed using categories (e.g., Associate Degree, Bachelor's degree), which do not capture attainment of shorter-term education goals or allow for documentation of having increased educational participation in terms of courses completed, additional semesters or years of education, or any other smaller increments of attainment. Finally, the form collects information on gross changes in employment (i.e., entering and leaving a job, moving from part-time to full-time), but no other positive employment outcomes such as increases in hours worked per week, hourly wage, or overall income, nor does it include any information about participation in volunteer work. These kinds of changes take time, and given the timeframe for implementing a common data collection system and the timing of the evaluation, the observation period was too short for these improvements to have occurred for most participants.

Recommendations: Revise the assessment form to include information about wages, hours and participation in volunteer work, attending college, and years of education instead of categories of educational attainment. Identify and consistently use a standardized assessment tool for measuring changes in prevocational and vocational abilities or "employability." Continue the evaluation over a longer time period to continue to document outcomes that take a year or more to accomplish.

(C) Client and family satisfaction with services provided.

The project sites, for the most part, have routinely collected information about customer satisfaction, but these were not consistent across sites. The evaluation designed and implemented a customer satisfaction survey of participants; however, other than in site visit interviews, the evaluation did not assess family or caregiver satisfaction with project services.

Recommendations: Routinely assess participant satisfaction with services provided across all sites using the TBI Project customer satisfaction survey that now exists. Develop and implement a customer satisfaction survey to be completed by family members (or other caregivers if family members are not available).

(D) Number of clients, family members, health and social service professionals, law enforcement professionals, and other persons receiving education and training designed to improve their understanding of the nature and consequences of TBI, as well as any documented outcomes of that training and education.

The project's quarterly site statistics summary includes the number of individuals who participate in site-sponsored training activities, by audience type. However, documenting the outcomes of that training and education has been beyond the resources of the sites.

Recommendation: Include assessment of TBI Project education and training outcomes in future evaluation efforts.

Conclusion

Using \$1.1 million in DMH funding, plus another \$228,000 in DR funding, the seven TBI Project sites served 610 participants with moderate to severe impairments from TBI in FY03-04. Evaluation results show that virtually all participants experienced at least some improvement in community reintegration after enrolling in the project, with participants at some sites experiencing substantial changes in their ability to take care of themselves at home, socialize with friends and family, and participate in community activities. Almost three-quarters of participants in the evaluation sample saw at least one improvement in their lives, whether it was securing a more stable source of income, finding a job, or moving into a more independent living situation, while only 20% experienced at least one negative change over time. Further evidence of the impact of the project on the lives of TBI survivors is the overwhelmingly positive ratings and comments that participants submitted on the evaluation's customer satisfaction survey.

In addition, the TBI Project sites provided information and referral services to almost 7,000 TBI survivors, caregivers/family, and professionals across the state and nation. They also provided TBI education to more than 2,000 professionals and a similar number of TBI survivors and their family members in their local communities.

The recommendations presented above recognize the value of the TBI Project's contribution, while also recognizing that there are a number of areas where the program can be improved. We must also acknowledge that the evaluation was limited in its ability to document outcomes by limitations in the available data and resources. The program offers great promise for addressing what are otherwise critical unmet needs of TBI survivors that help them to maintain and increase their community reintegration, while also providing significant community education services. The evaluation suggests the program is sufficiently successful that its expansion to reach more participants would be a good investment, but only if part of that investment is also targeted at program improvements to increase program benefits and improved data collection and reporting efforts to document those benefits.

Appendix A-1

Supplemental Tables on Evaluation Sample

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 1a
Characteristics of Project Participants at Intake

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
AGE AT INTAKE																
Mean	41		43		46		40		41		37		36		42	
Median	42		42		46		41		44		36		35		44	
SEX																
• Male	145	68%	32	60%	20	63%	21	84%	8	73%	34	74%	11	58%	19	73%
• Female	67	32%	21	40%	12	38%	4	16%	3	27%	12	26%	8	42%	7	27%
RACE																
• White	166	78%	37	70%	25	76%	23	92%	9	82%	39	85%	16	84%	17	65%
• African-American	7	3%	1	2%	2	6%	1	4%	1	10%	1	2%	0	0%	1	3%
• Hispanic	19	9%	9	17%	4	12%	0	0%	0	0%	1	2%	1	5%	4	15%
• Asian/ Pacific	9	4%	3	6%	0	0%	0	0%	0	0%	4	9%	2	11%	0	0%
• Native American	4	2%	2	4%	2	6%	0	0%	0	0%	0	0%	0	0%	0	0%
• Other	8	4%	1	2%	0	0%	1	4%	1	9%	1	2%	0	0%	4	15%
PRIMARY LANGUAGE																
• English	206	97%	52	98%	32	97%	24	96%	11	100%	44	96%	19	100%	24	92%
• Spanish	4	2%	1	2%	1	3%	1	4%	0	0%	0	0%	0	0%	1	4%
• Asian/ Pacific	2	1%	0	0%	0	0%	0	0%	0	0%	2	4%	0	0%	0	0%
• Other	1	1%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	4%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 1b
Characteristics of Project Participants at Intake

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
EDUCATION																
• > High School Grad	24	11%	7	13%	3	9%	2	8%	2	18%	7	15%	1	5%	2	8%
• HS Grad/GED	70	33%	19	36%	15	46%	8	32%	4	36%	16	35%	3	16%	5	19%
• Some College	68	32%	16	30%	8	24%	8	32%	2	18%	12	26%	13	68%	9	35%
• Associate Degree	5	2%	2	4%	0	0%	0	0%	0	0%	3	7%	0	0%	0	0%
• BA	38	18%	7	13%	6	18%	6	24%	3	27%	6	13%	2	11%	8	31%
• Grad School	5	2%	0	0%	1	3%	0	0%	0	0%	2	4%	0	0%	2	8%
• Unknown	3	1%	2	4%	0	0%	1	4%	0	0%	0	0%	0	0%	0	0%
MARITAL STATUS																
• Single	131	62%	31	56%	20	61%	16	64%	10	91%	22	48%	13	68%	19	73%
• Married	38	18%	15	28%	1	3%	5	20%	1	9%	12	26%	3	16%	1	4%
• Separated	5	2%	0	0%	2	6%	0	0%	0	0%	3	7%	0	0%	0	0%
• Divorced	37	17%	7	13%	10	30%	4	16%	0	0%	8	17%	3	16%	5	19%
• Widowed	2	1%	0	0%	0	0%	0	0%	0	0%	1	2%	0	0%	1	4%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 1c
Characteristics of Project Participants at Intake

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
INCOME																
• No Income	15	7%	6	11%	7	22%	1	4%	0	0%	1	2%	0	0%	0	0%
• SSDI	45	22%	12	23%	9	28%	6	25%	0	0%	11	25%	2	11%	5	19%
• SSI	65	31%	19	36%	9	28%	9	38%	4	40%	9	21%	3	16%	12	46%
• AFDC	1	1%	1	2%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
• General Relief	4	2%	0	0%	1	3%	0	0%	1	10%	1	2%	0	0%	1	4%
• Workers Comp.	11	5%	1	2%	1	3%	5	21%	0	0%	3	7%	1	5%	0	0%
• Employment	5	2%	1	2%	0	0%	0	0%	0	0%	0	0%	2	11%	2	8%
• Family	29	14%	12	23%	2	6%	3	13%	2	20%	3	7%	4	21%	3	12%
• Other (SDI)	23	11%	1	2%	1	3%	0	0%	3	30%	8	18%	0	0%	0	0%
• Pension/ Retirement	10	5%	0	0%	2	6%	0	0%	0	0%	8	18%	0	0%	0	0%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 1d
Characteristics of Project Participants at Intake

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
LIVING SITUATION																
• Alone	56	26%	14	26%	10	30%	9	36%	3	27%	7	15%	2	11%	11	42%
• Spouse	41	19%	14	26%	2	6%	5	20%	1	9%	14	30%	3	16%	2	8%
• Dependent Child	5	2%	1	2%	1	3%	1	4%	0	0%	1	2%	1	5%	0	0%
• Adult Child	5	2%	2	4%	2	6%	0	0%	0	0%	0	0%	0	0%	1	4%
• Parent/ Family	57	27%	12	23%	2	6%	7	28%	3	27%	19	41%	8	42%	6	23%
• Friend/ Roommate	22	10%	2	4%	5	15%	1	4%	2	18%	3	7%	4	21%	5	19%
• Transitional Living	1	1%	0	0%	0	0%	0	0%	1	9%	0	0%	0	0%	0	0%
• Other	2	1%	1	2%	1	3%	0	0%	0	0%	0	0%	0	0%	0	0%
• Board & Care	4	2%	1	2%	1	3%	0	0%	0	0%	2	4%	0	0%	0	0%
• SNF	6	3%	3	6%	2	6%	1	4%	0	0%	0	0%	0	0%	0	0%
• Attendant	1	1%	0	0%	0	0%	1	4%	0	0%	0	0%	0	0%	0	0%
• Institution	2	1%	2	4%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
• Homeless	11	5%	1	2%	7	21%	0	0%	1	9%	0	0%	1	5%	1	4%
SUBSTANCE ABUSE																
• Not at All	165	83%	45	87%	28	93%	19	79%	7	70%	26	68%	19	100%	21	84%
• Frequently	7	4%	4	8%	0	0%	0	0%	0	0%	3	8%	0	0%	0	0%
• Sometimes	13	7%	3	6%	1	3%	3	13%	1	10%	2	5%	0	0%	3	12%
• Suspected	13	7%	0	0%	1	3%	2	8%	2	20%	7	18%	0	0%	1	4%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 1e
Characteristics of Project Participants at Intake

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
HISTORY MENTAL ILLNESS	19	23%	-	-	-	-	8	33%	2	20%	6	15%	2	25%	1	33%
HISTORY SEIZURES	25	24%	1	33%	-	-	7	29%	4	40%	6	13%	2	29%	5	24%
HAS TRANSPORTATION	144	92%	41	93%	-	-	20	91%	4	50%	43	96%	14	100%	22	96%
AVERAGE INCOME AT INTAKE	72	\$659	21	\$194	32	\$832	4	\$1094	3	\$749	1	\$0	6	\$810	5	\$1054

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Table 2
Additional Participant Characteristics

CHARACTERISTIC	TOTAL		Clooney		CCCIL		CCNBC		Headway		Mercy		St. Jude		Pomeroy	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
HISTORY MENTAL ILLNESS	(n=84) 19	23%	-	-	-	-	(n=24) 8	33%	(n=10) 2	20%	(n=39) 6	15%	(n=8) 2	25%	(n=3) 1	33%
HISTORY SEIZURES	(n=103) 25	24%	(n=3) 1	33%	-	-	(n=24) 7	29%	(n=10) 4	40%	(n=46) 6	13%	(n=7) 2	29%	(n=13) 5	24%
HAS TRANSPORTATION	(n=156) 144	92%	(n=44) 41	93%	-	-	(n=22) 20	91%	(n=8) 4	50%	(n=45) 43	96%	(n=14) 14	100%	(n=23) 22	96%
• Drive Self	(n=156) 43	27%	(n=44) 14	33%	-	-	(n=22) 3	14%	(n=8) 1	13%	(n=45) 14	31%	(n=14) 7	X%	(n=23) 4	17%
• Friend/Family	(n=155) 61	39%	(n=44) 16	36%	-	-	(n=22) 11	50%	(n=7) 1	14%	(n=45) 25	56%	(n=14) 5	50%	(n=23) 3	13%
• Public Transportation	(n=155) 56	36%	(n=44) 16	36%	-	-	(n=22) 11	50%	(n=7) 2	29%	(n=45) 6	13%	(n=14) 3	36%	(n=23) 18	78%
SAFETY EQUIPMENT	(n=85) 60	71%	(n=28) 24	86%	-	-	(n=12) 6	50%	(n=3) 2	67%	(n=18) 13	72%	(n=11) 10	21%	(n=13) 5	39%
AVERAGE INCOME AT INTAKE	(n=72) 72	\$659	(n=21) 21	\$194	(n=32) 32	\$832	(n=4) 4	\$1094	(n=3) 3	\$749	(n=1) 1	\$0	(n=6) 6	\$810	(n=5) 5	\$1054

Independent Evaluation of the Traumatic Brain Injury Services of California

**Table 3a
Participant Characteristics Related to Injury**

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
AGE AT INJURY																
Mean	32		31		33		28		27		35		28		29	
Median	29		29		37		22		22		33		28		27	
YEARS SINCE INJURY AT INTAKE																
Mean	10.1		11.4		14.2		11.7		13.4		1.9		7.9		15.4	
Median	4.2		6.5		7.5		8.9		14.8		.65		2.5		9.0	
CAUSE OF INJURY																
• Car Accident	114	54%	22	42%	17	53%	15	60%	6	60%	29	63%	13	68%	12	46%
• Motorcycle	21	10%	7	13%	3	9%	4	16%	1	10%	5	11%	1	5%	0	0%
• Gun/ Assault	24	11%	10	19%	4	13%	1	4%	1	10%	0	0%	2	11%	6	23%
• Sports	8	4%	2	4%	1	3%	1	4%	0	0%	0	0%	2	11%	2	8%
• Domestic Violence	5	2%	4	8%	0	0%	1	4%	0	0%	0	0%	0	0%	0	0%
• Fall	30	14%	8	15%	5	16%	3	12%	1	10%	8	17%	1	5%	4	15%
• Other	8	4%	0	0%	1	3%	0	0%	1	10%	4	9%	0	0%	2	8%
TBI RELATED TO SUBSTANCE ABUSE																
• No	129	62%	35	69%	24	73%	15	60%	9	82%	9	42%	11	61%	16	62%
• Yes	58	28%	13	26%	5	15%	6	24%	1	9%	19	42%	7	39%	7	27%
• Unknown	22	11%	3	6%	4	12%	4	16%	1	9%	7	16%	0	0%	3	12%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 3b
Participant Characteristics Related to Injury

CHARACTERISTIC	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
COMA																
• Never	65	31%	19	36%	14	45%	4	17%	4	36%	15	33%	5	26%	4	15%
• Yes	106	49%	30	57%	11	36%	7	29%	5	46%	28	61%	13	68%	12	46%
• Unknown	39	18%	4	8%	6	19%	13	54%	2	18%	3	7%	1	5%	10	39%
• Days of Coma																
Mean	35.83		58.72		30.14		70.76		21.52		20.20		15.17		28.23	
Median	18.00		28.00		14.00		73.00		9.00		14.00		14.00		17.50	
AMNESIA																
• Never	50	24%	33	62%	3	10%	3	13%	1	9%	3	7%	4	21%	3	12%
• Yes	76	36%	9	17%	12	39%	5	21%	1	10%	33	72%	11	58%	5	19%
• Unknown	84	39%	11	21%	16	52%	16	67%	9	82%	10	22%	4	21%	18	69%
• Days of Amnesia																
Mean	79.48		252.38		47.78		107.15		-		41.20		91.35		48.68	
Median	21.00		99.90		21.00		113.90		-		14.00		7.00		10.00	
HOSPITALIZED																
• Never	16	8%	1	2%	7	23%	2	8%	1	9%	2	4%	2	11%	1	4%
• Yes	159	76%	47	89%	17	55%	9	38%	7	64%	44	96%	17	90%	18	69%
• Unknown	35	17%	5	9%	7	23%	13	54%	3	27%	0	0%	0	0%	7	27%
• Days in Hospital																
Mean	103.66		180.08		74.62		142.46		81.01		57.31		54.23		82.55	
Median	49.00		99.90		33.30		99.90		33.30		35.00		33.30		35.00	

Table 4
Ever Substance Abuse Problem or Treatment

	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
EVER SUBSTANCE ABUSE PROBLEM	76	39%	11	21%	11	36%	9	39%	6	60%	22	54%	3	18%	14	54%
EVER SUBSTANCE ABUSE PROBLEM SINCE ENTRY	37	17%	8	15%	2	6%	5	20%	3	27%	13	28%	0	0%	6	23%
EVER SUBSTANCE ABUSE TREATMENT																
• % All Participants	24	11%	9	17%	4	12%	2	8%	3	27%	1	2%	1	5%	4	15%
• % Ever Problem	24	32%	9	82%	4	36%	2	22%	3	50%	1	5%	1	33%	4	29%
• % Problem Since Entry	14	38%	8	100%	1	50%	2	40%	0	0%	1	8%	0	0%	2	33%

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Table 5
Alcohol/Substance Abuse

	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
SUBSTANCE ABUSE	165	83%	45	87%	28	93%	19	79%	7	70%	26	68%	19	100%	21	84%
• Not at All	7	4%	4	8%	0	0%	0	0%	0	0%	3	8%	0	0%	0	0%
• Frequently	13	7%	3	6%	1	3%	3	13%	1	10%	2	5%	0	0%	3	12%
• Sometimes	13	7%	0	0%	1	3%	2	8%	2	20%	7	18%	0	0%	1	4%
• Suspected																
HISTORY OF SUBSTANCE ABUSE																
• Yes	70	34%	11	21%	11	35%	8	35%	6	55%	21	50%	3	18%	10	39%
• No	134	66%	42	79%	21	66%	15	65%	5	46%	21	50%	14	82%	16	62%
HOW LONG SUBSTANCE FREE (YEARS)																
Mean	4.95		3.5		8.89		5.53		1.42		1.05		0.83		10.39	
Median	1.33		2.5		6.0		2.0		1.0		0.16		0.83		14	
SUBSTANCE ABUSE INTERFERES WITH EMPLOYMENT																
• Yes	1	1%	0	0%	0	0%	1	11%	0	0%	0	0%	0	0%	0	0%
• No	70	99%	6	100%	11	100%	8	89%	8	100%	7	100%	9	100%	21	100%
PARTICIPANT RECEIVING SUBSTANCE ABUSE HELP																
• Yes	16	24%	4	40%	4	40%	2	29%	3	43%	0	0%	1	33%	2	14%
• No	51	76%	6	60%	6	60%	5	71%	4	57%	16	100%	2	67%	12	86%

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Independent Evaluation of the Traumatic Brain Injury Services of California

Table 6
Vocational Status at Intake

VOCATIONAL STATUS	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DR CLIENT	46	22%	15	29%	4	12%	12	48%	1	10%	3	7%	2	11%	9	35%
EMPLOYED	24	11%	1	2%	2	6%	2	8%	3	27%	4	9%	7	37%	5	19%
– Full Time	11	46%	1	100%	0	0%	1	50%	1	33%	2	50%	4	57%	2	40%
– Part Time	12	50%	0	0%	2	100%	1	50%	2	66%	2	50%	2	29%	3	60%
– Unknown	1	4%	0	0%	0	0%	0	0%	0	0%	0	0%	1	14%	0	0%
SUPPORTED EMPLOYMENT (part-time)	4	2%	0	0%	0	0%	3	12%	0	0%	0	0%	0	0%	1	4%
JOB TYPE*																
• Food Service	2	8%	-	-	0	0%	0	0%	1	33%	0	0%	1	14%	0	0%
• Janitorial	1	4%	-	-	0	0%	1	20%	0	0%	0	0%	0	0%	0	0%
• Clerical	1	4%	-	-	0	0%	1	20%	0	0%	0	0%	0	0%	0	0%
• Computer	1	4%	-	-	0	0%	0	0%	0	0%	0	0%	1	14%	0	0%
• Horticultural	1	4%	-	-	0	0%	1	20%	0	0%	0	0%	0	0%	0	0%
• Other	18	75%	-	-	1	100%	2	40%	2	67%	3	100%	5	71%	5	100%
ENROLLED VOCATIONAL PROGRAM	17	9%	0	0%	2	6%	4	16%	0	0%	5	11%	2	11%	4	18%
• Skills Training	5	36%	-	-	0	0%	2	50%	-	-	2	40%	0	0%	1	50%
• Pre-Vocational	7	50%	-	-	0	0%	2	50%	-	-	3	60%	1	50%	1	50%
• Other	2	14%	-	-	1	100%	0	0%	-	-	0	0%	1	50%	0	0%
EMPLOYABLE	32	23%	3	7%	3	14%	14	74%	2	25%	2	8%	5	31%	3	38%
DESIRE TO WORK	134	66%	13	26%	18	56%	21	88%	8	73%	32	74%	17	94%	25	100%
DESIRE NOT TO WORK	60	29%	26	53%	21	66%	2	8%	1	10%	6	14%	1	5%	3	12%

*Includes participants who are competitively employed as well as those in supported employment.

Independent Evaluation of the Traumatic Brain Injury Services of California

**Table 7
Presenting Needs at Intake**

Presenting Needs at Intake	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
• Counseling	95	45%	30	57%	13	39%	5	20%	6	55%	25	54%	3	16%	13	50%
• Self Help/ Support Groups	88	41%	23	43%	13	39%	3	12%	7	64%	21	46%	3	16%	18	69%
• Vocational Rehabilitation	86	40%	12	23%	12	36%	18	72%	1	9%	9	20%	13	68%	21	81%
• Medical Services/ Testing	84	39%	17	32%	11	33%	0	0%	6	55%	32	70%	4	21%	14	54%
• Day Program	61	29%	28	53%	7	21%	3	12%	1	9%	8	17%	2	11%	12	46%
• Housing Assistance	58	27%	16	30%	19	58%	7	28%	5	46%	0	0%	1	5%	10	39%
• Recreation	55	26%	16	30%	6	18%	7	28%	1	9%	5	11%	4	21%	16	62%
• Social Security	55	26%	18	34%	9	27%	2	8%	2	18%	6	13%	10	53%	8	31%
• Independent Living Skills	52	24%	4	8%	6	18%	11	44%	1	9%	16	35%	2	11%	12	46%
• Transportation	51	24%	9	17%	7	21%	8	32%	4	36%	8	17%	4	21%	11	42%
• Advocacy	45	21%	12	23%	3	9%	1	4%	9	82%	1	2%	15	79%	4	15%
• Funding Resources	34	16%	1	2%	7	21%	1	4%	1	9%	1	2%	8	42%	15	58%
• Legal Issues	23	11%	4	8%	1	3%	1	4%	2	18%	1	2%	2	11%	12	46%
• In-Home Assistance	22	10%	1	2%	2	6%	2	8%	4	36%	5	11%	0	0%	8	31%
• Substance Abuse	20	9%	7	13%	2	6%	1	4%	1	9%	7	15%	0	0%	2	8%
• Budgeting	18	9%	2	4%	2	6%	5	20%	1	9%	0	0%	0	0%	8	31%

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Independent Evaluation of the Traumatic Brain Injury Services of California

Table 7
Presenting Needs at Intake

Presenting Needs at Intake	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
• Crisis Intervention	17	8%	14	26%	0	0%	0	0%	1	9%	0	0%	0	0%	2	8%
• Other	17	8%	0	0%	0	0%	0	0%	2	18%	5	11%	4	21%	6	23%
• ESL Classes/ Education	15	7%	0	0%	0	0%	1	4%	0	0%	1	2%	8	42%	5	19%
• Community Education	15	7%	1	2%	2	6%	0	0%	0	0%	4	9%	0	0%	8	31%
• NeuroPsych Testing	14	7%	3	6%	2	6%	0	0%	1	9%	1	2%	0	0%	7	27%
• Hygiene/ Grooming	13	6%	3	6%	0	0%	3	12%	0	0%	1	2%	0	0%	6	23%
• Respite Care	6	3%	0	0%	0	0%	0	0%	0	0%	2	4%	0	0%	4	15%
• Protective Services	3	1%	1	2%	1	3%	0	0%	0	0%	0	0%	1	5%	0	0%
• Immigration Assistance	1	1%	1	2%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
• Aide Training	1	1%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	4%
AVERAGE NUMBER OF NEEDS																
Mean	4.48		4.21		3.79		3.16		5.09		3.53		4.42		8.58	
Median	4.00		4.00		3.00		2.00		4.00		3.00		4.00		7.50	

Table 8
Top 10 Participant's Needs: Change in Need Over Time

Type of Need	Needs (Intake)		Needs (6 Months)		Change at 6 months	Needs (12 Months)		Overall Change in Needs
	N	%	N	%	%	N	%	%
• Counseling	95	45%	55	42%	-3%	17	32%	-13%
• Self Help/ Support Groups	88	41%	47	36%	-5%	20	37%	-4%
• Vocational Rehabilitation	86	40%	45	35%	-5%	15	28%	-12%
• Medical Services/ Testing	84	39%	18	14%	-25%	4	7%	-32%
• Day Program	61	29%	30	23%	-6%	10	19%	-10%
• Housing Assistance	58	27%	24	11%	-16%	6	3%	-24%
• Recreation	55	26%	12	6%	-20%	2	1%	-25%
• Social Security	55	26%	29	22%	-4%	11	20%	-6%
• Independent Living Skills	52	24%	16	12%	-12%	4	7%	-17%
• Transportation	51	24%	14	11%	-13%	6	11%	-13%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 9
Services Used Between Intake & Six Months

Services Used	Total (n = 129)		Clooney (n = 53)		CCCIL (n = 18)		CCNBC (n = 8)		Headway* (n = 0)		Mercy (n = 22)		St. Jude (n = 9)		Pomeroy (n = 20)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
6 Months																
• Case Coordination	129	100%	53	100%	18	100%	8	100%	-	-	21	96%	9	100%	19	100%
• Specialized Evaluations	20	16%	3	6%	5	28%	2	25%	-	-	4	18%	2	22%	4	21%
• Structured Living Assistance	24	19%	13	25%	3	17%	3	38%	-	-	1	5%	1	11%	3	16%
• Mental Health Services	28	22%	15	28%	1	6%	2	25%	-	-	1	5%	1	11%	8	42%
• Substance Abuse Program	11	9%	9	17%	2	11%	0	0%	-	-	0	0%	0	0%	0	0%
• Social/ Recreational Program	52	40%	22	42%	10	56%	2	25%	-	-	6	27%	9	100%	3	16%
• Supported Employment (Pre-Placement)	5	4%	2	4%	1	6%	0	0%	-	-	0	0%	0	0%	2	11%
• Supported Employment (Post-Placement)	1	1%	1	2%	0	0%	0	0%	-	-	0	0%	0	0%	0	0%
• Employment Services	19	15%	4	8%	2	11%	4	50%	-	-	1	5%	2	22%	6	32%
• Educational Services	9	7%	0	0%	3	17%	1	13%	-	-	0	0%	2	22%	3	16%
• Day Program	53	41%	26	49%	8	44%	2	25%	-	-	4	18%	2	22%	11	55%
AVERAGE NUMBER OF SERVICES USED																
Mean	2.71		2.79		2.94		3.00		-		1.73		3.11		3.05	
Median	3.00		2.00		3.00		2.5		-		1.00		3.00		3.00	

* None of Headway's participants had been in the program long enough to have six month assessments.

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Table 10
Services Used Between Six & Twelve Months

12 Months Services Used	Total (n = 54)		Clooney (n = 26)		CCCIL (n = 6)		CCNBC (n = 1)		Headway* (n = 0)		Mercy (n = 13)		St. Jude (n = 3)		Pomeroy (n = 5)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
• Case Coordination	53	98%	26	100%	6	100%	1	100%	-	-	12	92%	3	100%	5	100%
• Specialized Evaluations	3	6%	1	4%	1	17%	0	0%	-	-	0	0%	1	33%	0	0%
• Structured Living Assistance	9	17%	7	27%	1	17%	1	100%	-	-	0	0%	0	0%	0	0%
• Mental Health Services	12	22%	8	31%	1	17%	0	0%	-	-	1	8%	0	0%	2	40%
• Substance Abuse Program	7	13%	4	15%	1	17%	0	0%	-	-	1	8%	0	0%	1	20%
• Social/ Recreational Program	22	41%	13	50%	5	83%	1	100%	-	-	1	8%	2	67%	0	0%
• Supported Employment (Pre-Placement)	2	4%	1	4%	0	0%	0	0%	-	-	0	0%	0	0%	1	20%
• Supported Employment (Post-Placement)	1	2%	0	0%	0	0%	0	0%	-	-	0	0%	0	0%	1	20%
• Employment Services	8	15%	2	8%	1	17%	1	100%	-	-	0	0%	1	33%	3	60%
• Educational Services	3	6%	0	0%	2	33%	0	0%	-	-	0	0%	0	0%	1	20%
• Day Program	28	52%	17	65%	4	66%	1	100%	-	-	2	15%	0	0%	4	80%
AVERAGE NUMBER OF SERVICES USED																
Mean	2.74		3.04		3.67		5.00		-		1.31		2.33		3.60	
Median	3.00		3.00		4.00		5.00		-		1.00		2.00		4.00	

* None of Headway's participants had been in the program long enough to have twelve month assessments.

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 11
**Community Integration Questionnaire (CIQ) Scores at Intake for
TBI Project Participants Enrolled Between February 1, 2003 and June 30, 2004**

	Total (n=213)		Clooney (n=53)		CCCIL (n=33)		CCNBC (n=25)		Headway (n=11)		Mercy (n=46)		St. Jude (n=19)		Pomeroy (n=26)	
	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean	Median
Total CIQ Score	13.37	14.0	9.89**	10.0**	14.85**	15.0**	17.4**	14.0**	12.55**	13.0**	13.22**	12.5**	16.63**	18.0**	12.96**	14.0**
Home Integration	4.52	4.0	2.92**	2.0**	5.85**	6.0**	6.8**	6.0**	4.64**	4.0**	3.83**	3.0**	5.47**	5.0**	4.35**	4.5**
Social Integration	6.65	7.0	5.3**	6.0**	6.91**	7.0**	7.48**	7.0**	5.55**	6.0**	7.72**	7.50**	7.16**	7.0**	6.46**	6.0**
Productivity	2.23	2.0	1.66**	2.0**	2.09**	2.0**	3.12**	2.0**	2.36**	2.0**	1.67**	2.0**	4.0**	5.0**	2.33**	2.0**

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Table 12
Average CIQ Scores for Evaluation Sample Participants with Six-Month Assessment Data

	Total (n=125)	Clooney (n=53)	CCCIL (n=18)	CCNBC (n=8)	Headway	Mercy (n=22)	St. Jude (n=9)	Pomeroy (n=15)
Total CIQ Score								
• Intake	12.65	9.89	14.50	18.75	–	13.41	17.11	13.05
• Six Months	14.65	11.75	14.67	20.00		17.23	20.22	14.87
• 12 Months (n = 49)	15.20	13.00	13.20	16.00		19.45	20.33	16.67
• %Change Intake - 6 Months	39.9%	62.6%	0.6%	7.8%		38.7%	63.9%	17.1%
• %Change Intake - 12 Months	47.2% (n = 49)	60.5% (n = 25)	-0.9% (n = 5)	23.1% (n = 1)		35.0% (n = 11)	92.4% (n = 3)	24.3% (n = 3)
Home Integration								
• Intake	4.14	2.92	5.56	7.38	–	3.64	6.22	4.40
• Six Months	4.86	3.34	5.67	7.38		5.23	8.22	5.40
• 12 Months (n = 49)	4.92	3.88	5.80	5.00		5.73	10.00	4.33
• %Change Intake - 6 Months	33.1%	13.6%	2.5%	0.0%		89.4%	130.8%	24.5%
• %Change Intake - 12 Months	49.5%	31.3%	17.5%	0.0%		122.5%	77.8%	-1.0%
Social Integration								
• Intake	6.39	5.30	6.94	8.00	–	8.00	6.44	6.35
• Six Months	7.23	6.43	7.00	8.50		8.73	7.44	7.33
• 12 Months (n = 49)	7.47	6.69	5.80	6.00		9.82	6.67	9.67
• %Change Intake - 6 Months	21.5%	22.6%	0.26%	6.9%		14.7%	93.0%	18.3%
• %Change Intake - 12 Months	29.3%	42.6%	-1.1%	0.0%		6.3%	58.9%	33.3%
Productivity								
• Intake	2.16	1.66	2.00	3.38	–	1.77	4.44	2.56
• Six Months	2.57	1.98	2.00	4.13		3.27	4.56	2.29
• 12 Months (n = 49)	2.82	2.42	1.60	5.00		3.91	3.67	2.67
• %Change Intake - 6 Months	29.6%	19.3%	2.8%	45.0%		94.1%	7.9%	-0.8%
• %Change Intake - 12 Months	61.2%	40.2%	-10.0%	150.0%		119.7%	95.0%	100.0%

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Table 13
Outcomes

OUTCOME	Total (n=130)		Clooney (n=53)		CCCIL (n=18)		CCNBC (n=8)		Headway (n=0)		Mercy (n=22)		St. Jude (n=9)		Pomeroy (n=20)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
TERMINATED	37	28%	0	0%	16	89%	0	0%	0	0%	20	91%	0	0%	1	5%
REASON TERMINATED																
• Goal Met	14	38%	-	-	7	44%	-	-	-	-	7	35%	-	-	0	0%
• Moved	8	22%	-	-	4	25%	-	-	-	-	4	20%	-	-	0	0%
• No Contact	3	8%	-	-	2	13%	-	-	-	-	1	5%	-	-	0	0%
• Participant Choice	7	19%	-	-	2	13%	-	-	-	-	4	20%	-	-	1	100%
• No Follow-Through	3	8%	-	-	1	6%	-	-	-	-	2	10%	-	-	0	0%
EMPLOYMENT CHANGE*																
• Ever Employed	32	25%	1	2%	2	11%	3	38%	3	0%	9	41%	8	89%	5	25%
• Any Job Change	11	34%	1	100%	0	0%	1	33%	0	0%	5	56%	1	13%	3	60%
– Employed Intake, Stopped Work	3	27%	1	100%	0	0%	0	0%	0	0%	0	0%	0	0%	2	67%
– Got Job 6 or 12 Mos	8	72%	0	0%	0	0%	1	100%	0	0%	5	100%	1	100%	1	33%
<i>Part-Time</i>	3	27%	0	0%	0	0%	0	0%	0	0%	2	40%	1	100%	1	33%
<i>Full-Time</i>	5	46%	0	0%	0	0%	1	100%	0	0%	3	60%	0	0%	0	0%
EDUCATION CHANGE																
• Any Change Education	7	3%	1	2%	1	3%	0	0%	0	0%	2	4%	1	5%	2	8%
– HS/GED to Some College	5	71%	1	100%	1	100%	0	0%	0	0%	1	50%	0	0%	2	100%
– Some College to Associates Degree	1	14%	0	0%	0	0%	0	0%	0	0%	0	0%	1	100%	0	0%
– BA to Some Graduate School	1	14%	0	0%	0	0%	0	0%	0	0%	1	50%	0	0%	0	0%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 13
Outcomes

OUTCOME	Total (n=130)		Clooney (n=53)		CCCIL (n=18)		CCNBC (n=8)		Headway (n=0)		Mercy (n=22)		St. Jude (n=9)		Pomeroy (n=20)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DAY PROGRAM CHANGE																
• Ever Day Program	74	57%	29	55%	11	61%	6	75%	0	0%	7	32%	7	78%	14	70%
• Any Change Day Prog	50	68%	28	97%	3	27%	2	33%	0	0%	6	86%	1	14%	10	71%
– Increase Participation	42	84%	27	96%	2	67%	0	0%	-	-	3	50%	0	0%	10	100%
– Decrease Participation	8	16%	1	4%	1	33%	2	100%	-	-	3	50%	1	100%	0	0%
VOCATIONAL PROGRAM CHANGE																
• Ever Voc Program	25	19%	0	0%	2	11%	5	63%	0	0%	6	27%	3	33%	9	45%
• Any Voc Prog Change	9	36%	0	0%	0	0%	1	20%	-	-	2	33%	1	33%	5	56%
– Increase Participation	6	67%	0	0%	0	0%	1	100%	-	-	0	0%	1	100%	4	67%
– Decrease Participation	3	33%	0	0%	0	0%	0	0%	-	-	2	100%	0	0%	1	20%

Independent Evaluation of the Traumatic Brain Injury Services of California

Table 13
Outcomes

OUTCOME	Total (n=130)		Clooney (n=53)		CCCIL (n=18)		CCNBC (n=8)		Headway (n=0)		Mercy (n=22)		St. Jude (n=9)		Pomeroy (n=20)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
DEPARTMENT OF REHAB CHANGE																
• Ever DR	61	47%	19	36%	4	22%	14	57%	1	0%	6	27%	4	44%	13	65%
• Any Change DR	22	36%	8	36%	1	5%	3	14%	0	0%	3	14%	3	14%	4	18%
– Increase Participation	10	45%	4	50%	0	0%	1	33%	-	-	1	33%	1	33%	3	75%
– Decrease Participation	12	54%	4	50%	1	100%	2	67%	-	-	2	67%	2	67%	1	25%
LIVING SITUATION CHANGE																
• Any Move	19	19%	1	2%	5	15%	2	8%	-	-	5	11%	2	10%	4	15%
– Family to Alone/ Dependent Child	4	21%	1	100%	0	0%	0	0%	-	-	1	20%	1	50%	1	25%
– Family/Spouse to Friend/ Roommate	5	26%	0	0%	0	0%	1	50%	-	-	4	80%	0	0%	0	0%
– Homeless to Not Homeless	4	21%	0	0%	3	60%	0	0%	-	-	0	0%	1	50%	0	0%
– Alone to With Friend/ Roommate	2	11%	0	0%	0	0%	1	50%	-	-	0	0%	0	0%	1	25%
– SNF or Friend/ Roommate to Alone	2	11%	0	0%	1	20%	0	0%	-	-	0	0%	0	0%	1	25%
– Family/Spouse to Inst./Board Care	2	10%	0	0%	1	20%	0	0%	-	-	0	0%	0	0%	1	25%

Independent Evaluation of the Traumatic Brain Injury Services of California

**Table 13
Outcomes**

OUTCOME	Total (n=130)		Clooney (n=53)		CCCIL (n=18)		CCNBC (n=8)		Headway (n=0)		Mercy (n=22)		St. Jude (n=9)		Pomeroy (n=20)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
INCOME SOURCE CHANGE																
• Any Income Change	24	11%	6	11%	4	12%	2	8%	-	-	6	13%	1	5%	5	19%
– None/GA to SSDI/SSI	5	21%	3	50%	1	25%	0	0%	-	-	0	0%	0	0%	1	20%
– None to GA	1	4%	0	0%	1	25%	0	0%	-	-	0	0%	0	0%	0	0%
– Family to SSDI/SSI	6	25%	3	50%	1	25%	0	0%	-	-	1	17%	0	0%	1	20%
– SDI to SSDI/SSI	2	8%	0	0%	0	0%	0	0%	-	-	1	17%	0	0%	1	20%
– Moved to Employment	6	25%	0	0%	0	0%	2	100%	-	-	3	50%	1	100%	0	0%
– Moved to Family Support	3	13%	0	0%	1	25%	0	0%	-	-	1	17%	0	0%	1	20%
– SDI to Pension	1	4%	0	0%	0	0%	0	0%	-	-	0	0%	0	0%	1	20%
CIQ CHANGE (intake-6 mo)	(n = 125)		(n = 53)		(n = 18)		(n = 8)		(n = 0)		(n = 22)		(n = 9)		(n = 15)	
• Home																
Mean	.712		.415		.111		0				1.59		2.00		.800	
Median	0		0		0		0		-		1.00		0		1.00	
• Social																
Mean	.792		1.13		.056		.500				.727		1.00		.600	
Median	0		0		0		0		-		1.00		0		0	
• Productivity																
Mean	.447		.321		0		.750				1.50		.111		-1.54	
Median	0		0		0		0		-		1.00		0		0	
• Total																
Mean	1.97		1.87		.167		1.25				3.82		3.11		1.47	
Median	1.00		0		0		0		-		3.00		1.00		1.00	

*Includes one person who started supported employment job. All other in supported employment had not been in program long enough to have changed.

Table 14
Change in the Number of Needs Over Time

	Total	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
INTAKE-6 MONTH	(n = 130)	(n = 53)	(n = 18)	(n = 8)		(n = 22)	(n = 9)	(n = 15)
Mean	-1.64	-1.38	-.400	-.375	-	-.857	0.00	-5.30
Median	-1.00	0.00	0.00	0.00		-1.00	0.00	-3.00
6 MONTH-12 MONTH	(n = 54)	(n = 26)	(n = 6)	(n= 1)		(n = 13)	(n = 3)	(n = 5)
Mean	-.628	-.682	-1.25	-1.00	-	0.00	0.00	-1.50
Median	0.00	0.00	-.500	-1.00		0.00	-1.00	-1.00
INTAKE-12 MONTH	(n = 54)	(n = 26)	(n = 6)	(n= 1)		n = 13)	(n = 3)	(n = 5)
Mean	-1.78	-1.95	-1.75	-1.00	-	-.727	0.00	-5.25
Median	-1.00	-1.50	-1.50	-1.00		0.00	0.00	-5.00

Table 15
Percent of Customers with Presenting Need at Intake vs. Follow-up

Presenting Need	Intake (N = 213)	6 Months (n = 130)	12 Months (n = 54)	% Change Intake to 12 Mo F-Up
Day Program	29%	23%	19%	-10%
Counseling	45%	42%	32%	-13%
Substance Abuse Treatment	9%	7%	13%	+4%
Recreation	26%	9%	4%	-22%
Vocational Rehabilitation	40%	35%	28%	-12%
Self Help/ Support Groups	41%	36%	37%	-4%
Medical Services/ Testing	39%	14%	7%	-32%
Housing Assistance	27%	19%	11%	-16%
Social Security	26%	22%	20%	-6%
Independent Living Skills	24%	12%	7%	-17%
Transportation	24%	11%	11%	-13%
Advocacy	21%	16%	9%	-12%
Funding Resources	16%	7%	4%	-12%
Legal Issues	11%	7%	2%	-9%
In-Home Assistance	10%	4%	2%	-8%
Budgeting	9%	5%	6%	-3%
Crisis Intervention	8%	5%	2%	-6%
Other	8%	5%	6%	-2%
ESL Classes/ Education	7%	5%	2%	-5%
Community Education	7%	6%	9%	+2%
NeuroPsych Testing	7%	2%	2%	-5%
Hygiene/ Grooming	6%	5%	0%	-6%
Respite Care	3%	0%	0%	3%
Protective Services	1%	2%	2%	+1%
Immigration Assistance	1%	0%	0%	-1%
Aide Training	1%	0%	0%	-1%

Appendix A-2

**Supplemental Tables on
Fiscal Year 2003-2004 Site Statistics**

Independent Evaluation of the Traumatic Brain Injury Services of California

Table A
Total Individuals Served by the Project*
 (source: Fiscal Year 2003-2004 Site Statistics)

PARTICIPANTS RECEIVING SERVICES YEARLY	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Less than 12 months	338	213	32	25	27	NA	13	28
13 months – 2 years	52	8	1	0	0	NA	17	26
25 months – 5 years	83	46	0	0	0	NA	28	9
61 months – 8 years	70	38	18	0	0	NA	14	0
Over 8 years	25	11	0	0	0	NA	14	0
Unduplicated Total Number of Participants	610	316	51	25	27	42	86	63
Persons Receiving Info/Referral	6888	5694	258	32	102	188	453	161
Total Number of Outreach Attendees	7772	713	1981	106	746	495	2990	741
Total Individuals Served	15270	6723	2290	163	875	725	3529	965

*The count of participants is unduplicated, however, the number of I&R and community education/service recipients may count individuals more than once.

Independent Evaluation of the Traumatic Brain Injury Services of California

Table B
Intakes, Assessments and Service Plans
 (source: Fiscal Year 2003-2004 Site Statistics)

Service	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Intakes and Initial Assessments:								
Number of Intakes	363	123	22	22	34	55	75	32
Average Hours per Intake	0.9	0.9	0.9	0.6	1.2	0.9	0.6	1.9
Number of Initial Assessments	202	34	18	27	27	44	17	35
Ratio of Initial Assessments to Intakes	0.6	0.3	0.8	1.2	0.8	0.8	0.2	1.1
Average Hours per Initial Assessment	1.2	1.1	0.5	0.6	1.6	1.4	1.5	1.3
6, 12, and 18-Month Assessments:								
Number of 6 Month Assessments	106	12	14	5	7	33	16	19
Average Hours per 6 Month Assessment	0.8	2.0	0.5	0.5	0.8	0.5	0.8	0.6
Number of 12-Month Assessments	90	5	8	0	0	35	17	25
Average Hours per 12 Month Assessment	0.6	1.6	0.5	-	-	0.5	0.9	0.5
Number of 18 Month Assessments	71	1	1	0	0	43	11	15
Average Hours per 18 Month Assessment	0.6	1.0	.5	-	-	0.5	0.6	0.7
Number of Annual Assessments (active cases only)	98	7	18	0	0	0	46	27
Average Hours per Annual Assessment (in 1 hour units)	0.7	1.6	0.5	-	-	-	0.7	0.5
Individual Service Plans:								
Number of Newly Written ISPs	369	35	21	5	28	30	17	233
Average Hours per New ISP	0.6	1.0	0.4	1.2	0.8	0.8	0.4	0.4
Ratio of New ISPs to Initial Assessments	1.0	0.3	1.0	0.2	0.8	0.6	0.2	7.3
Number of Updated/Re-Served ISPs	361	19	35	6	37	25	23	216
Average Hours per updated ISP	0.5	1.3	0.5	1.3	0.6	0.8	0.3	0.4

Independent Evaluation of the Traumatic Brain Injury Services of California

Table C
Average Total Hours of Core Participant Services Provided Per Quarter*
 (source: Fiscal Year 2003-2004 Site Statistics)

	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Community Reintegration Services:								
Average Hours/Participant/Quarter	4.0	1.0	2.0	58.8	2.4	5.3	2.2	5.9
Supportive Living Services								
Average Hours/Participant/Quarter	3.5	1.8	2.1	13.2	7.7	5.3	1.1	2.6
Vocational Supportive Services								
Average Hours/Participant/Quarter	11.7	4.3	0.9	16.2	6.0	19.4	1.0	15.7
Case Coordination Services								
Average Hours/Participant/Quarter	1.9	1.0	1.6	6.6	2.7	2.9	1.4	4.2

* This figure reports the average hours of service provided per participant per quarter for each site. Because the site statistics do not provide an unduplicated count of participants who received each service across quarters, it is not possible to calculate the average per year.

Independent Evaluation of the Traumatic Brain Injury Services of California

Table D
Community Services
 (source: Fiscal Year 2003-2004 Site Statistics)

	TOTAL	Clooney	CCCIL	CCNBC	Headway	Mercy	St. Jude	Pomeroy
Number Volunteer Placements	53	2	2	0	0	10	9	30
Number Competitive Job Placements	25	3	3	3	1	5	5	5
Total Outreach & Community Service Presentations	478	57	101	3	117	47	79	74
Total Number of Outreach & Community Service Attendees	7772	713	1981	106	746	495	2990	741
Total Hours of Outreach & Community Services	1866.3	212.5	481.8	55.5	197.0	96.5	613.0	210.0

Appendix A-3

Supplemental Table on Participant Satisfaction Survey

Independent Evaluation of the California Traumatic Brain Injury Project

Appendix A-3
Results of the Customer Satisfaction Survey

	Total (n = 160)		Clooney (n = 14)		CCCIL (n = 15)		CCNBC (n = 15)		Headway (n = 22)		Mercy (n = 18)		St. Jude (n = 50)		Pomeroy (n = 24)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
SURVEY SAMPLE																
• Surveys Sent	402		112		41		23		43		49		82		52	
• Surveys Completed	160		14		15		15		22		18		50		24	
• Return Rate	40%		13%		37%		65%		51%		37%		61%		48%	
WHO COMPLETED																
• TBI Survivor	124	82%	8	57%	15	100%	10	83%	20	91%	14	82%	39	80%	18	82%
• Family	24	16%	5	36%	0	0%	2	18%	1	5%	3	18%	9	18%	4	18%
• Caregiver	3	2%	1	7%	0	0%	0	0%	1	5%	0	0%	1	2%	0	0%
TREATED WITH RESPECT																
1. Strongly Agree	121	78%	14	100%	10	67%	12	80%	13	59%	15	83%	43	88%	14	61%
2. Agree	28	18%	0	0%	4	27%	3	20%	7	32%	2	11%	4	8%	8	35%
3. Neither Agree/ Disagree	4	3%	0	0%	0	0%	0	0%	1	5%	1	6%	1	2%	1	4%
4. Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
5. Strongly Disagree	3	2%	0	0%	1	7%	0	0%	1	5%	0	0%	1	2%	0	0%
Mean	1.31		1		1.53		1.2		1.59		1.22		1.2		1.43	
Median	1		1		1		1		1		1		1		1	
RECEIVED INFO AND ASSISTANCE																
1. Strongly Agree	102	65%	13	93%	9	64%	8	53%	10	46%	13	72%	37	74%	12	52%
2. Agree	36	23%	1	7%	3	21%	6	40%	8	36%	3	17%	8	16%	7	30%
3. Neither Agree/ Disagree	14	9%	0	0%	1	7%	1	7%	3	14%	2	11%	4	8%	3	13%
4. Disagree	2	1%	0	0%	0	0%	0	0%	1	5%	0	0%	0	0%	1	4%
5. Strongly Disagree	2	1%	0	0%	1	7%	0	0%	0	0%	0	0%	1	2%	0	0%
Mean	1.5		1.07		1.64		1.53		1.77		1.39		1.40		1.70	
Median	1		1		1		1		2		1		1		1	

Independent Evaluation of the California Traumatic Brain Injury Project

Appendix A-3
Results of the Customer Satisfaction Survey

	Total (n = 160)		Clooney (n = 14)		CCCIL (n = 15)		CCNBC (n = 15)		Headway (n = 22)		Mercy (n = 18)		St. Jude (n = 50)		Pomeroy (n = 24)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
RECEIVED CLEAR INFORMATION																
1. Strongly Agree	100	64%	13	93%	9	60%	9	60%	10	46%	13	72%	36	72%	1	44%
2. Agree	48	31%	1	7%	5	33%	5	33%	9	41%	5	28%	12	24%	11	48%
3. Neither Agree/ Disagree	7	5%	0	0%	0	0%	1	7%	3	14%	0	0%	1	2%	2	9%
4. Disagree	1	1%	0	0%	0	0%	0	0%	0	0%	0	0%	1	2%	0	0%
5. Strongly Disagree	1	1%	0	0%	1	7%	0	0%	0	0%	0	0%	0	0%	0	0%
Mean	1.44		1.07		1.60		1.47		1.68		1.28		1.34		1.65	
Median	1		1		1		1		2		1		1		2	
SERVICES PLANNED FOR GOALS																
1. Strongly Agree	89	57%	13	93%	9	60%	9	60%	10	46%	11	61%	29	58%	8	35%
2. Agree	46	29%	1	7%	2	13%	3	20%	10	46%	5	28%	13	26%	12	52%
3. Neither Agree/ Disagree	16	10%	0	0%	3	20%	3	20%	2	9%	0	0%	7	14%	1	4%
4. Disagree	4	3%	0	0%	0	0%	0	0%	0	0%	2	11%	0	0%	2	9%
5. Strongly Disagree	2	1%	0	0%	1	7%	0	0%	0	0%	0	0%	1	2%	0	0%
Mean	1.62		1.07		1.80		1.60		1.64		1.61		1.62		1.87	
Median	1		1		1		1		2		1		1		2	
DEAL MORE EFFECTIVELY																
1. Strongly Agree	83	53%	8	62%	9	60%	7	47%	8	36%	12	67%	31	62%	8	35%
2. Agree	41	26%	3	23%	3	20%	6	40%	6	27%	4	22%	11	22%	8	35%
3. Neither Agree/ Disagree	23	15%	2	15%	3	20%	2	13%	4	18%	1	6%	7	14%	4	17%
4. Disagree	7	5%	0	0%	0	0%	0	0%	3	14%	1	6%	0	0%	3	13%
5. Strongly Disagree	2	1%	0	0%	0	0%	0	0%	1	5%	0	0%	1	2%	0	0%
Mean	1.74		1.54		1.60		1.67		2.23		1.50		1.58		2.09	
Median	1		1		1		2		2		1		1		2	

Independent Evaluation of the California Traumatic Brain Injury Project

Appendix A-3
Results of the Customer Satisfaction Survey

	Total (n = 160)		Clooney (n = 14)		CCCIL (n = 15)		CCNBC (n = 15)		Headway (n = 22)		Mercy (n = 18)		St. Jude (n = 50)		Pomeroy (n = 24)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
BETTER CONTROL OF LIFE																
1. Strongly Agree	85	55%	10	71%	6	40%	7	47%	9	41%	11	65%	34	69%	8	35%
2. Agree	36	23%	1	7%	3	20%	4	27%	6	27%	4	24%	9	18%	9	39%
3. Neither Agree/ Disagree	28	18%	3	21%	6	40%	4	27%	4	18%	1	6%	6	12%	4	17%
4. Disagree	6	4%	0	0%	0	0%	0	0%	3	14%	1	6%	0	0%	2	9%
5. Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Mean	1.71		1.50		2.00		1.80		2.05		1.53		1.43		2.00	
Median	1		1		2		2		2		1		1		2	
WOULD USE SERVICES AGAIN																
1. Strongly Agree	108	69%	14	100%	10	67%	10	67%	13	59%	11	61%	36	78%	11	48%
2. Agree	36	23%	0	0%	5	33%	2	13%	6	27%	5	28%	8	16%	10	44%
3. Neither Agree/ Disagree	8	5%	0	0%	0	0%	3	20%	2	9%	0	0%	2	4%	1	4%
4. Disagree	3	2%	0	0%	0	0%	0	0%	1	5%	1	6%	0	0%	1	4%
5. Strongly Disagree	2	1%	0	0%	0	0%	0	0%	0	0%	1	6%	1	2%	0	0%
Mean	1.44		1.00		1.33		1.53		1.59		1.67		1.32		1.65	
Median	1		1		1		1		1		1		1		2	
WOULD RECOMMEND TO OTHERS																
1. Strongly Agree	123	78%	14	100%	10	67%	10	67%	16	73%	14	78%	43	86%	14	70%
2. Agree	25	16%	0	0%	4	27%	4	27%	3	14%	3	17%	6	12%	5	22%
3. Neither Agree/ Disagree	5	3%	0	0%	1	7%	1	7%	1	5%	0	0%	1	2%	1	4%
4. Disagree	3	2%	0	0%	0	0%	0	0%	2	9%	0	0%	0	0%	1	4%
5. Strongly Disagree	1	1%	0	0%	0	0%	0	0%	0	0%	1	6%	0	0%	0	0%
Mean	1.31		1.00		1.40		1.40		1.50		1.39		1.16		1.43	
Median	1		1		1		1		1		1		1		1	

Independent Evaluation of the California Traumatic Brain Injury Project

Appendix A-3
Results of the Customer Satisfaction Survey

	Total (n = 160)		Clooney (n = 14)		CCCIL (n = 15)		CCNBC (n = 15)		Headway (n = 22)		Mercy (n = 18)		St. Jude (n = 50)		Pomeroy (n = 24)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
RATE ASSISTANCE																
1. Excellent	118	75%	14	100%	10	67%	10	67%	14	64%	15	83%	41	82%	14	58%
2. Good	22	14%	0	0%	3	20%	4	27%	4	18%	1	6%	5	10%	5	21%
3. Fair	14	9%	0	0%	1	7%	1	7%	4	18%	1	6%	3	6%	4	17%
4. Poor	3	2%	0	0%	0	0%	0	0%	0	0%	1	6%	1	2%	1	4%
5. Unacceptable	1	1%	0	0%	1	7%	0	0%	0	0%	0	0%	0	0%	0	0%
Mean	1.40		1.00		1.60		1.40		1.55		1.33		1.28		1.67	
Median	1		1		1		1		1		1		1		1	

Appendix B

Assessment and Intake Forms

California Traumatic Brain Injury Project Independent Evaluation

Participant Data Collection Plan

The evaluation will focus on grant participants served during the FY July 1, 2003 through June 30, 2004. Some of the individuals served during this timeframe may have entered the project prior to the beginning of this fiscal year. These individuals will be included in the sample if their initial assessment included a CIQ (which was implemented in February 2003.)

The Sample

The primary criterion for inclusion in BPA's evaluation sample is that the participant's Intake and Initial Assessment were conducted between February 2003 and June 2004 and include the CIQ. This criterion will ensure that the evaluation has access to baseline information for all participants served during FY 2003-04. (Participants included in this sample may include a few individuals who did not receive services during the key analysis period of June 2003 through June 2004. Depending upon the number of participants in this group, the evaluation may drop such individuals from the analysis.)

The Data

For each participant in the sample, the data will include:

1. Intake (for all individuals whose initial assessment was during the 2/03 to 6/04 timeframe.)
2. Initial Assessment (including CIQ—conducted during 2/03 to 6/04 timeframe)
3. Follow-up Assessments for 6 and 12 months (including CIQ—for individuals whose initial and subsequent assessments were conducted during the 2/03 to 6/04 timeframe.)

Data Submission Schedule

Most of the grantees maintain the intake and assessments as paper forms. Project staff will photocopy the forms and send the copies to BPA for data entry.¹ Grantees will send data for each participant only once.

By July 15, 2004, Please send intake and assessment forms for all participants

If you have any questions, please contact Sherry Almandsmith (510) 465-7884, sherry@bpacal.com, or Linda Toms Barker (808) 934-9297, Linda@bpacal.com.

Intake Dates for Evaluation Data “Batches” by Follow-Up

	Batch	
	March 31, 2004	June 30, 2004
6 Month Follow-Up	Feb. 2003 – Sept. 2003	Oct. 2003 – Dec. 2003
12 Month Follow-Up	Feb. 2003 – March 2003	April 2003 – June 2003

¹ St Jude apparently has this information in an electronic version. We will make arrangements for the data to be emailed or sent on a disk or CD.

**California Department of Mental Health
Traumatic Brain Injury Projects**

ASSESSMENT

Name _____ D.O.I. _____ I.D. # _____

Initial Date: _____ 6 Month Date: _____ 12 Month Date: _____ 18 Month Date: _____

1. Agency: *(circle one)* **STJBIN MGH RCH BCF CCCIL MHW CCNBC**

2. Last 4 digits on participant's social security number:

3. Participant's Date of Birth: _____(m/d/y) Age _____

4. Gender: *(circle one)* **M**ale **F**emale

5. Racial/Ethnic Group: *(circle one)*

<u>(A)</u> CAUCASIAN	<u>(B)</u> AFRICAN-AMERICAN	<u>(C)</u> HISPANIC
<u>(D)</u> ASIAN/PACIFIC	<u>(E)</u> NATIVE AMERICAN	<u>(O)</u> OTHER

6. Is the participant a client of Dept. of Rehabilitation? *(check one for each time period)*

Counselor/Office:

INITIAL	<u>Y</u> ES	<u>N</u> O	HAS APPLIED	<u>U</u> NKNOWN
6 MONTHS	<u>Y</u> ES	<u>N</u> O	HAS APPLIED	<u>U</u> NKNOWN
12 MONTHS	<u>Y</u> ES	<u>N</u> O	HAS APPLIED	<u>U</u> NKNOWN
18 MONTHS	<u>Y</u> ES	<u>N</u> O	HAS APPLIED	<u>U</u> NKNOWN

7. What is the *primary* language of the participant? *(circle one)*

(A) ENGLISH **(B)** SPANISH **(C)** ASIAN/PACIFIC **O**THER _____ **U**NKNOWN

8. What is the participant's highest level of education? *(check one for each time period) Counselor/Office)*

	INITIAL	6 MO.	12 MO.	18 MO
<u>(A)</u> Less than high school diploma				
<u>(B)</u> High school or GED				
<u>(C)</u> Some college or post high school/technical/vocational				
<u>(D)</u> Associate Degree				
<u>(E)</u> College graduate (BA)				
<u>(F)</u> Some graduate school				
<u>U</u> NKNOWN				

Comments: _____

9. What is the participant's marital status? *(check one for each time period)*

	INITIAL	6 MO.	12 MO.	18 MO,
<u>(A)</u> Single				
<u>(B)</u> Married				
<u>(C)</u> Separated				
<u>(D)</u> Divorced				
<u>(E)</u> Widowed				
<u>U</u> nknown				

10. Is the participant eligible for MediCal? *(check one for each time period)*

	INITIAL	6 MO.	12 MO.	18 MO.
<u>Y</u> es				
<u>N</u> o				

11. Is the participant currently using MediCal? *(check one for each time period)*

	INITIAL	6 MO.	12 MO.	18 MO,
<u>Y</u> es				
<u>N</u> o				

12. What was the participant's age at onset of injury? _____

13. How did client receive injury? (check one)

(A) Automobile/Truck Accident	
(B) Motorcycle Accident	
(C) Alcohol or Drug related	
(D) Gunshot wound or Assault	
(E) Sports related	
(F) Domestic Violence	
(G) Fall	
No motor vehicle	
Unknown	

14. Was participant's injury drug or alcohol related?
(check one)

Yes	
No	
Not Applicable	
Unknown	

15. What is different about Participant since injury?

Physical	
Cognitive	
Emotional	

16. How long was participant in coma? (fill in amount)

	Never
	Hours
	Days
	Weeks
	Months
	Unknown

17. How long was participant's amnesia? (fill in amount)

	Never
	Hours
	Days
	Weeks
	Months
	Unknown

18. How long was participant hospitalized? (fill in amount)

	Never
	Hours
	Days
	Weeks
	Months
	Unknown

19. What is participant's primary source of income
(check one for each time period)

INITIAL 6 MO. 12 MO. 18 MO

(A) SSDI				
(B) SSI				
(C) AFDC				
(D) Gen. Relief				
(E) VA Benefits				
(F) Workers C.				
(G) Pension				
(H) Employ.				
(I) Family				
No Income				
Other				
Unknown				

20. Current Living Situation (check one only)

INITIAL 6 MO. 12 MO. 18MO.

(A) Alone				
(B) Spouse				
(C) Dep. Child.				
(D) Adult Child.				
(E) Paren/Fam.				
(F) Frnd/room.				
(G) Trans. Liv.				
(H) Other				
(I) B/Care				
(J) SNF				
(K) Attendant				
(L) Institution				
(M) Homeless				
(U) Unknown				

EMPLOYMENT

For initial, describe the average circumstances of the participant in the 90 days prior to program intake. For 6 months and 12 months, describe the average circumstances of the participant at those times. Please *circle* the correct response to each question.

21. Is participant Competitively Employed?

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
6 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
12MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
18 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>

22. Is Competitive Employment

<u>FT</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>FT</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>FT</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>FT</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>

23. Is participant in Supported Employment?

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
6 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
12 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
18 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>

24. Is Supported Employment

<u>ET</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>ET</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>ET</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>
<u>ET</u>	<u>PT</u>	<u>Unknown</u>	<u>Not Ap</u>

26. Is participant in Vocational Program? (circle one)

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
6 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
12 MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>
18MO	<u>Yes</u>	<u>No</u>	<u>Unknown</u>	<u>Not Ap</u>

25. If participant is employed, what type of position is it?

	INIT'L	6 MO	12 MO	18 MO
Food Service				
Janitorial				
Clerical				
Computer				
Cashiering				
Horticultural				
Other (describe)				

27. Type of Vocational Program

	INITIAL	6 MO	12 MO	18MO
Skills Tr.				
Pre-Voc				
Emp Prep				
Other				

28. Is participant employable at this time?

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
6 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
12 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
18MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A

29. Has participant expressed a desire to work?

INIT'L	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
6 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
12 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
18 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A

30. Has participant expressed a desire NOT to work?

INIT'L	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
6 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
12 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
18 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A

31. Please comment on work situation/ work history

DAY PROGRAM

32. Does the participant attend a Day Program?

	INITIAL	6 MO	12 MO	18MO
<u>(A)</u> Does not attend a Day Program				
<u>(B)</u> Attends 1 Day Per Week				
<u>(C)</u> Attends 2 to 3 Days Per Week				
<u>(D)</u> Attends 4 to 5 Days Per Week				
<u>(U)</u> Unknown				

33. Has participant applied to a Day Program?

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
6 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
12 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
18MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A

34. Is participant interested in going to a Day Program?

INITIAL	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
6 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
12 MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A
18MO	<u>Yes</u>	<u>No</u>	<u>Unk</u>	N/A

ALCOHOL/SUBSTANCE ABUSE35. Does alcohol or drug abuse interfere with day-to-day functioning? (*check one*)

	Initial	6 MO	12 MO	128MO
<u>(A)</u> Frequently				
<u>(B)</u> Sometimes				
<u>(C)</u> Not at all				
<u>(D)</u> Unknown				
<u>(E)</u> Unknown-Suspected/Reported				
<u>(F)</u> Not Applicable				

36. Past history of alcohol/drug abuse. Yes_____ No_____

How long alcohol & drug free. _____Mo. _____Yrs. _____N/A

37. Does Alcohol/drug abuse interfere with employment?

INITIAL	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
6MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
12 MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
18 MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A

38. Is participant receiving help for alcohol/drug abuse?

INITIAL	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
6 MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
12 MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A
18MO	<u>Y</u> es	<u>N</u> o	<u>U</u> nk	N/A

39. Please describe alcohol/drug program. _____

HAND SCORING INSTRUCTIONS FOR QUESTION #40

1. **HOME INTEGRATION SECTION (Q1-5):** Enter appropriate score for each question , add scores and enter in Home Integration Total box.
2. **SOCIAL INTEGRATION TOTAL (Q6-11):** Enter appropriate score for each question, add scores and enter in Social Integration Total box.
3. **PRODUCTIVITY TOTAL Q12-15):** Q12-Enter score in appropriate box, Q13-15 Enter ONLY ONE score from table below in the appropriate box, add these score and enter in Productivity Total box.

JOB/SCHOOL	Score
Not working, not looking for work, not going to school, no volunteer activities	0
Volunteers 1-4 times a month AND not working, not looking for work, not in school	1
Actively looking for work AND/OR volunteers 5 or more times a month	2
Attends school part-time OR working part-time (less than 20 hours a week	3
Attends school full time OR works full-time	4
Works full-time AND attends school part-time OR Attends school full-time AND works part-time (less than 20 hours a week)	5

IF RETIRED SCORE AS:

In the past month, how often did you engage in volunteer activities?

Answer	Score
5 or more	4
1-4 times	2
Never	0

40. COMMUNITY INTEGRATION QUESTIONNAIRE-(write answer# in appropriate box)

Question	Answer	Initial	6 Mo.	12 Mo.	18 Mo.
1. Who usually does shopping for groceries or other necessities in your household?	2-Yourself alone 1-Yourself & someone else 0-Someone else				
2. Who usually prepares meals in your household?	2- Yourself alone 1-Yourself & someone else 0-Someone else				
2. In your home who usually does normal everyday housework?	2-Yourself alone 1-Yourself & someone else 0-Someone else				
3. Who usually cares for the children in your home?	2-Yourself alone 1-Yourself & someone else 0-Someone else				
Score for * = (Q1+Q2+Q3+Q5)/4	*-N/A (0 less than 17)				
4. Who usually plans social arrangements such as get- togethers with family and friends?	2-Yourself alone 1-Yourself & someone else 0-Someone else				
HOME INTEGRATION TOTAL(Add 1-5)					
6. Who usually looks after your personal finances, such as banking or paying bills?	2-Yourself alone 1-Yourself & someone else 0-Someone else				
7. Approximately how many times a month you now usually participate in shopping outside your home?	2-5 or more times 1-1-4 times 0-Never				
8. Approximately how many times a month you now usually participate in leisure activities such as movies, sports, restaurants, etc.?	2-5 or more times 1-1-4 times 0-Never				
9. Approximately how many times a month you now usually visit friends & relatives?	2-5 or more times 1-1-4 times 0-Never				
10. When you participate in leisure activities do you usually do this alone or with others?	2-Family & friends 2-Friends without head injury 1-Mostly family 1-Mostly friends with head inj 0-Mostly alone				
11. Do you have a best friend with whom you confide?	2-Yes 0-No				
SOCIAL INTEGRATION TOTAL(Add 6-11)					
12. How often do you travel outside the home?	2-Almost every day 1-Almost every week 0-Seldom/never (<1/wk)				
13. Please choose the answer that best corresponds to your current (during the past month) work situation.	F/T (>20 hrs/wk) P/T (<20 hrs/wk) Not wk, actively looking Not wk, not looking N/A-Retired due to age	<i>(See scoring on previous page)</i>			
14. Please choose the answer that best corresponds to your current (during the past month) school or training program.	F/T program P/T program No school/training N/A-Retired due to age				
15. In the past month, how often did you engage in volunteer activities?	5 or more times 1-4 times Never				
PRODUCTIVITY TOTAL (12+Variable Score)					
TOTAL SCORE					

PRESENTING PROBLEM41. What are the participant's present needs? *(check all that apply)*

	INITIAL	6 MO	12 MO	18 MO
(1) Day Program				
(2) Housing Assistance				
(3) Counseling				
(4) Transportation				
(5) Medical Services/Testing				
(6) Immigration Assistance				
(7) ESL Classes/Education				
(8) Recreation				
(9) Vocational Rehabilitation				
(10) Social Security				
(11) Community Education				
(12) Independ. Living Skills				
(13) Advocacy				
(14) Protective Services				
(15) Hygiene/Grooming				
(16) Funding Resources				
(17) Crisis Intervention				
(18) In-Home Assistance				
(19) Substance Abuse				
(20) Legal Issues				
(21) Respite Care				
(22) Aide Training				
(23) Budgeting				
(24) Self Help/Sup. Groups				
(25) NeuroPsych Testing				
(26) Other				

42. What is the reason for the participant's continuation of need?

6 MO:
12MO
18 MO:

43. Participant's current level of participation? *(check one for each time period)*

	6 MO	12MO	18 MO
1. Active			
2. On rolls, inactive			
3. Terminated			
4. Terminated against advice			

44. What services has participant received? *(check one for each time period)*

	6 MO	12MO	18MO
Case Coordination			
Specialized Evaluations			
Structured Living Assistance			
Mental Health Services			
Substance Abuse Program			
Social/Recreational Program			
Supported Employment (Pre-placement)			
Supported Employment (Post-placement)			
Employment Services			
Educational Services			

DMH-Traumatic Brain Injury Projects
INTAKE

SJBIN MGH RCH BCF CCCIL MHW CCNBC

STAFF RECEIVING CALL:	
CALLER'S NAME	
CALLER'S Ph#	
TODAY'S DATE:	
REFERRED BY:	
EMERGENCY CONTACT:	

ID#	
SS#	

APPLICANT	
ADDRESS	
CITY,STATE,ZIP	
PHONE #	
E-MAIL	

RELATION TO CALLER

	101	WIFE
	102	HUSBAND
	201	DAUGHTER
	202	DTR-IN-LAW
	301	SON
	302	SON-IN-LAW
	401	BROTHER
	402	SISTER
	501	MOTHER
	502	FATHER
	90	SELF
	91	OTHER (PROF)
	92	FRND/NGHBOR
	U	UNKNOWN

LIVING ARRANGEMENT

	A	ALONE
	B	SPOUSE
	C	DEPEND CHILDREN
	D	ADULT CHILDREN
	E	PARENT/FAMILY
	F	FRND/ROOMMATE
	G	TRANS LIVING
	H	OTHER (<i>describe</i>)
	I	BOARD & CARE
	J	SNF
	K	ATTENDANT
	L	INSTITUTION
	M	HOMELESS
	U	UNKNOWN

GENDER

	M	MALE
	F	FEMALE

DOB	
AGE	

MARITAL STATUS

	A	SINGLE
	B	MARRIED
	C	SEPARATED
	D	DIVORCED
	E	WIDOWED
	U	UNKNOWN

ETHNICITY

	A	CAUCASIAN
	B	AFRICAN-AMER
	C	HISPANIC
	D	ASIAN/PACIFIC
	E	NATIVE AMER
	O	OTHER
	U	UNKNOWN

LANGUAGE

	A	ENGLISH
	B	SPANISH
	C	ASL
	O	OTHER
	U	UNKNOWN

SAFETY EQUIP WORN
(SEATBELT/HELMET)

	YES
	NO
	UNKNOWN
	N/A

DIAGNOSIS

	A	TRAUMATIC BI
	B	TUMOR/BRAIN
	C	CVA
	D	ENCEPHALITIS
	E	ANOXIA
	O	OTHER
	U	UNKNOWN

TYPE OF ACCIDENT

	A	AUTO/TRUCK
	B	MOTORCYCLE
	C	ALCOHOL/DRUG
	D	GUN/ASSAULT
	E	SPORTS
	F	DOM VIOLENCE
	G	FALL
	N	NO MOTOR VEHCL
	U	UNKNOWN

ALCOHOL INVOLVED

	YES
	NO
	UNKNOWN
	N/A

DATE INJURY	
AGE/ONSET	
INS.	
AM'T INCOME	

NOTES

PCP		
MHH		
MEDS		
SEIZURES		

MEDICAL ELIG.

	YES
	NO

PROGRAM ELIG.

	YES
	NO

SOURCE OF INCOME

	A	SSDI
	B	SSI
	C	AFDC
	D	GENERAL RELIEF
	E	VA BENEFITS
	F	WORKERS COMP
	G	PENSION
	H	EMPLOYMENT
	I	FAMILY
	N	NO INCOME
	O	OTHER
	U	UNKNOWN

NEEDS REQUESTED

	1	DAY PROGRAM
	2	HOUSING ASSISTANCE
	3	COUNSELING
	4	TRANSPORTATION
	5	MEDICAL SERVICE
	6	IMMIGRAT. ASSISTANCE
	7	ESL CLASSES/EDUCATION
	8	RECREATION,PSY, SOCIAL
	9	VOCATIONAL REHAB
	10	SOC SEC BENEFITS
	11	TBI GEN INFORMATION
	12	PROTECTIVE SERVICES
	13	HYGEINE/GROOMING
	14	FUNDING RESOURCES
	15	CRISIS INTERVENTION
	16	IN-HOME ASSISTANCE

	17	SUBSTANCE ABUSE
	18	LEGAL ISSUES
	19	RESPIRE CARE
	20	AIDE TRAINING
	21	COMMUNITY ED.
	22	BUDGETING
	23	IND. LIVING SKILLS
	24	SELF HELP GROUPS
	25	ADVOCACY
	26	OTHER

TRANSPORTATION

OWN CAR		PUBLIC	
FRIENDS/FAM		OTHER	
DRV LIC-YES		NO	

REFERRALS: _____ **UNITS** _____

RVSD: 7/14/03 MS WORD _____

Appendix C

Customer Satisfaction Survey and Protocols

Independent Evaluation of the California Traumatic Brain Injury Project

Protocol for Administering Customer Satisfaction Survey

Each grantee will survey all current participants as of May 1, 2004. The survey instrument is not designed to be completed by individuals with severe cognitive impairments, and the projects do not have the resources to accommodate these participants. Thus, participants without cognitive impairments will likely complete the survey themselves, while the caregivers of other participants may complete the survey on behalf of the participant. Project staff should not assist participants in completing the survey.

The survey instrument is designed so that each grantee can insert the name of its project at the top of the form. Grantees will mail the survey to participants on or before August 20, 2004. Participants will be asked to return the survey to BPA in an enclosed self-addressed envelope by August 31, 2004.

Each grantee will include its own cover letter with the survey. An example cover letter is attached. The cover letter should ask participants to comment on their experience with the program, so that their feedback can be used to improve project services. The letter will also instruct respondents to return the survey to BPA using a self-addressed envelope, and will stress that the confidentiality of survey responses will be guarded, and that no names will be associated with specific answers. In summary – each participant will receive an envelope containing:

- The survey;
- The cover letter; and
- A postage-paid envelope addressed to BPA.

To ensure a high response rate to the survey, the grantees will make follow-up phone calls to remind participants to complete and return the surveys. Staff should be prepared to mail a second copy of the survey packet to participants who ask for them. Grantees may use one of two approaches to conduct the follow-up calls:

1. Call everyone to whom survey was sent about one week after the survey was mailed to remind and encourage them to return the survey.
2. Assign identification numbers for all participants, BPA will report back which surveys (by ID number) were returned so that project staff can contact only those participants who have not yet returned their surveys, about one week after the survey was mailed.
 - a. Grantees will assign identification numbers for all participants, maintain a log of names and IDs, and write the ID number on the upper right hand corner of each survey.
 - b. BPA will report back to the grantees which surveys (by ID number) were returned, so that project staff can contact those participants who have not yet returned their surveys.

Grantees that choose to use ID numbers have the option of building into the identification code one key descriptive factor of their choosing (e.g., employment services vs. nonvocational services, which case manager the participant works with, etc.). BPA will tabulate the survey results for each project as a whole, as well as by the descriptive factor chosen by the project.

* IF the program participant needs assistance completing the survey, please answer on behalf of the person with TBI.

(Project Name)
Customer Satisfaction Survey

Who is the person completing this survey?

☐ TBI Survivor

☐ Family Member*

☐ Caregiver*

Please answer the following questions by marking the box that you feel best expresses your opinion.

1. I was treated with respect.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
2. I received the information and assistance I needed.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
3. I was given information clearly and in a way I could understand.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
4. Services were planned with my goals and needs in mind.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
5. As a result of the services I received, I deal more effectively with daily problems.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
6. I am better able to control my life since participating in the program.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
7. If I needed to, I would be willing to use program services again.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
8. I would recommend this program to other TBI survivors.	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
9. Overall, the assistance I received was:	Excellent	Good	Fair	Poor	Unacceptable

If you would like to make any other comments about the program or the services you received, please use the space below or the back of this survey.

Appendix D

Site Visit Protocol and Topic Guides

California Traumatic Brain Injury (TBI) Project Independent Evaluation

Site Visit Activities and Interviews

- Tour of facilities and overview of project services
- Observation of project services
- Interviews with:

Respondent	Estimated Time Needed	Topics
Project Director	3 hours	Project goals, organization and service model; staffing; methods for collecting and using participant data; public & professional education efforts; development of community resources; collaborating agencies and types of collaboration
Executive Director of Grantee Organization	45 minutes	Grantee relationships in local community, context of project, design of service model, project implementation experience
Staff who complete Intake	1 hour	Eligibility and selection criteria, intake and assessment processes
Staff who do Functional Assessment	1 hour	Assessment process for mobility, communication skills, psychosocial adjustment, cognitive functioning, and assistance/service needs
Case Coordinators	1 hour	Service needs of participants, individual service planning process, collaboration with other agencies, participant outcomes
Community Reintegration Staff	1 hour	Participant ADL and IADL service needs, barriers, and challenges; services provided; participant independence and integration outcomes
Supported Living Staff	1 hour	Participant ADL and IADL service needs, services provided, participant independence and integration outcomes
Vocational Support Staff	1 hour	Service needs of participants, types of services provided (prevocational, educational, employment), participant vocational outcomes
Finance person	30 minutes	Third party reimbursements
Data person	1 hour	Methods for collecting and using participant data; arrangements for BPA obtaining site data
Project Participants (3)	20-30 minutes each	Service needs of participants, customer satisfaction
Caregivers of Participants (3 – 5)	1 hour for focus group	Service needs of participants, customer satisfaction
Representatives of collaborating agencies (e.g., DR, mental health, community-based organizations)	30-45 minutes each	Types of collaborations, agency roles, interagency communications, impact of project services and collaboration on participants and local disability community

Traumatic Brain Injury Project
Site Visit Schedule

	Site	Program Contact	Confirmed Date	Notes
Name Grantee Location	New Options Central Coast CIL Santa Cruz	Michael Bradshaw , IL Services Team Manager 831-462-8720, Ext. 815 fax: 831-462-8727 mbradshaw@cccil.org	Feb 23-24 (Mon – Tues)	Rescheduled for March 29-30 With Linda (?)
Name Grantee Location	St. Jude Brain Injury Network St. Jude Medical Center Fullerton	Jana Gable , Project Coordinator 714-449-4848 fax: 714-447-0987 jgable@sjf.stjoe.org	April 19-20 (Mon – Tues)	
Name Grantee Location	Project Connections Betty Clooney Foundation Long Beach	Robert Almaraz , Executive Director 562-938-9005 fax: 562-938-9211 bcbftbi@aol.com	April 21-22 (Wed-Thurs)	
Name Grantee Location	Coordinated Care Project Mercy Healthcare Sacramento	Lynda Eaton , Client Services Liaison 916- 536-2442 fax: 916-780-5770 leaton@chw.edu	Jan 27-28 (Tues – Wed)	With Jane
Name Grantee Location	San Francisco TBI Network RCH, Inc. San Francisco	Terri Ragual , Program Supervisor 415-665-4100, ext. 1728 fax: 415-665-3800 tragual@rchinc.org	Feb 11-12 (Wed–Thurs)	With Jane
Name Grantee Location	Making Headway (same) Eureka	Amy Wright , Program Director 707-442-7668 fax: 707-443-8839 headway@reninet.com	March 22-23 (Mon – Tues)	
Name Grantee Location	Options Central Coast Neurobehav Ctr Morro Bay	Robin Pry , Program Coordinator 805-772-6066 fax: 805-772-6067 rpryt@optionsccnbc.org	Feb 17-18 (Tues-Wed)	

California Traumatic Brain Injury (TBI) Project Independent Evaluation

Site Visit Topic Guides

Project Director

*marked in yellow items that it may be possible to get from others (and put * next to highest priority for PD. Getting the yellow items from the PD might be a luxury. Maybe tell the PD that you have a long list of questions and he/she should feel free to mention another staff person who can also answer that question in the interest of time*

1. * Personal background and experience (what doing prior, how came to this role)
2. * Project goals and service model
3. * Staffing – number of staff, FTE, roles, education and experience staff strengths you look for and reward
4. * Budget and funding sources, third party reimbursements, sustainability
5. * Target population, eligibility and selection criteria, waiting list
6. * Geographic service area
7. * Collaboration with other agencies/Referrals - - where do participants come from? Other type of relationships, types of agencies, challenges and successes,
8. Walk-through of service process – intake, assessment, service plans, community reintegration services, supported living, vocational services, case coordination –brief overview. Get more detail from case manager.
9. When is applicant considered to be a participant? When is s/he officially “done” with program?- Ask of intake/assessment/case mgr/ and data person also.
10. Typical length of services/participation
11. * Implementation experience – challenges and successes
12. Total number participants served to date, overview of demographics, functional challenges
13. Overview of participant outcomes – ADLs, community participation, living arrangements, vocational, educational May be sufficient to just ask in #18 below.
14. move up earlier
15. * Public and professional education efforts (support groups, workshops for professionals or community in general, outreach, community networking) – how many, what type, number attending, community impact
16. * Existing customer satisfaction measures and results (both participants and caregivers)
17. * Participant data – how project collects, maintains, and uses information on participant characteristics, services used, and outcomes
18. Evaluation data collection arrangements (data quality? Relevance to program? issues or concerns?)
19. * Overall impact of project on participants, caregivers, community
20. * Innovative or promising practices
21. * Lessons

Executive Director of Grantee Organization

1. Personal background and experience (?)
2. Community context – economy, demographics
3. Organization background and context - - target population, range of services (especially TBI/disability services, employment services)
4. Why applied for grant
5. Pre-existing relationships with other community agencies (before grant award)
6. Design of service model (new vs. building on existing services)
7. Level of integration of project services with rest of what grantee does
8. Project implementation experience
9. Project funding sources, adequacy, sustainability
10. Overall impact of project on participants, caregivers, community
11. Innovative or promising practices
12. Lessons

Intake Staff

1. Personal background and experience
2. FTE, roles and responsibilities (work for project only, or both grantee and project, intake only vs. other project services)
3. Referral sources, by type and frequency
4. Eligibility criteria, selection process, level of demand/waiting list
5. Functional status of “typical” applicant
6. Intake process and relationship to assessment (e.g., before, after, same time?)
7. When is applicant considered to be a participant? When considered to be a “closed” case?
8. Project implementation experience
9. Innovative or promising practices
10. Lessons

Assessment Staff

1. Personal background and experience
2. FTE, roles and responsibilities (work for project only, or both grantee and project)
3. Timing of assessment within project’s service process – typical length of assessment process
4. When is applicant considered to be a participant? When considered to be a “closed” case?
5. Assessment process for mobility, communication skills, psychosocial adjustment, cognitive functioning, vocational skills/goals, and assistance/service needs
6. Types of instruments, tests, specialists used for assessment
7. Does the project ever do “assessment only”?
8. Funding sources for assessment beyond grant funds (e.g., health insurance, VR)
9. Project implementation experience
10. Innovative or promising practices
11. Lessons

Case Coordinators

1. Personal background and experience
2. FTE, roles and responsibilities (work for project only, or both grantee and project, case mgt only or other project services,)
3. At what point in the service process do case coordinators become involved with the participant?
4. Overview of service needs of participants
5. Walk-through of service process – intake, assessment, service plans, community reintegration services, supported living, vocational services, case coordination
6. Service planning process – level of participant direction vs. caregiver direction, at what point in process, how often updated
7. Typical length of services/participation in program
8. Collaboration and coordination with other service providers and agencies
9. Project implementation experience
10. Innovative or promising practices
11. Lessons

Community Reintegration Staff

1. Personal background and experience
2. FTE, roles and responsibilities (work for project only, or both grantee and project, case mgt only or other project services,)
3. At what point in the service process do community reintegration (and/or supported living) staff become involved with the participant?
4. Participant ADL and IADL service needs
5. Other barriers/service needs related to community reintegration
6. Services provided
7. Typical length of services/participation in community integration services
8. How are “supported living” services defined, how many participants get them? How organized and delivered?
9. Limitations to services project can provide, unmet needs
10. Participant reintegration outcomes (independent living, self direction, community integration)
11. Innovative or promising practices
12. Lessons

Vocational Support Staff

1. Personal background and experience
2. FTE, roles and responsibilities (work for project only, or both grantee and project, case mgt only or other project services,)
3. At what point in the service process do vocational support staff become involved with the participant?
4. Proportion of clients who participate in vocational services
5. Service needs of participants – if relevant, how similar to or different from other vocational clients.
6. Types of services provided (prevocational, educational, employment, supported employment)
7. Typical length of services/participation in vocational services
8. Employer relationships and marketing efforts
9. Participant vocational outcomes
10. Project implementation experience
11. Innovative or promising practices
12. Lessons

Financial Manager

1. Budget and funding sources
2. Third party reimbursements
3. Fiscal management issues/concerns (timeliness of payment, income sufficient to cover costs, etc.)

Data/MIS Staff

1. Relationship between project data and grantee data
2. Methods for collecting and using participant data
3. Definitions of services, participants, closures, outcomes, etc.
4. Data reports/output - - Total number participants served to date, overview of demographics, functional challenges, services received, length of program participation, outcomes (ADLs, community participation, living arrangements, vocational, educational)
5. Quarterly reports to DMH – how compile and define items
6. Issues or concerns about evaluation, data collection, data quality
7. Suggestions for improvements

Project Participants

1. Current status - - participant, former participant, types of services receiving now, employment/training status, etc.
2. Service needs
3. Services received
4. Customer satisfaction
5. Continuing unmet needs
6. Suggestions for improvements

Caregivers

1. Service needs of participants
2. Services received
3. Customer satisfaction
4. Continuing unmet needs
5. Suggestions for improvements

Community Partners/Collaborating Agencies

1. What your agency does
2. Description of relationship with grantee, roles, collaboration efforts, and how they came about.
3. Overall impact of project on participants, caregivers, community
4. Innovative or promising practices
5. Lessons
6. Suggestions for improvements